



AN ABSTRACT OF THE DISSERTATION OF

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Title: Mothering a Child With Autism in the United States and in South Korea.

Abstract approved:

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In this dissertation, I qualitatively examined the meaning of mothering a child with autism in two countries: the United States and South Korea. The overarching research question focused on how sociocultural ideas about mothering and disability, particularly autism spectrum disorders, shape women's understanding of themselves and their children with disabilities.

In the first study, using symbolic interactionism and feminism, I examined (a) how middle-class, White women who have children with autism understand themselves as mothers and (b) how their ideas are shaped by social interactions with others. Through in-depth interviews with 12 women who have children with autism, I found that these mothers understand themselves to be empathic supporters, mediators, and advocates for their children with autism. Their stories are shaped by selective

attention to those who support their self image and a disregard of those who undermine it. Implications for policy and practice are offered.

In the second study, guided by the integration of feminist and disability theories within a social constructionist framework, I asked (a) how dominant sociocultural systems related to mothering and disability shape South Korean mothers' understanding of themselves and their children with autism and (b) how mothers conform to and resist these systems. To answer these questions, I conducted in-depth interviews with 14 middle-class, South Korean mothers with children who have autism. I found that these mothers resisted stigmatizing attitudes toward themselves and their children and they reconstructed the meaning of "normal" childhood by relying on a network of similarly situated mothers. They described themselves as "good" by adhering to Confucian family values that encourage women to sacrifice themselves to focus on their children's success.

From these findings, the two studies collectively demonstrate that mothering a child with autism is (a) gendered, (b) specific to ones' understanding of autism, and (c) both oppressing and empowering to women. The overarching implications for policy and practice are offered.

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Mothering a Child With Autism in the United States and in South Korea

by

Hyun-Kyung You

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I understand that my dissertation will become part of the permanent collection of Oregon State University libraries. My signature below authorizes release of my dissertation to any reader upon request.

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Hyun-Kyung You, Author

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## CONTRIBUTION OF AUTHORS

Lori A. McGraw and Katherine A. MacTavish are the co-authors of the first manuscript, *Striving to Be a Better Mother: Women Who Have Children with Autism*. They offered conceptual, methodological, and analytic advice to the study. For the second manuscript, *The Intersection of Motherhood and Disability: Being a “Good” Korean Mother to an “Imperfect” Child*, Lori A. McGraw is the co-author. She provided conceptual, methodological, and analytic guidance to the study.



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## DEDICATION

I dedicate this dissertation to my mother, Jong-Bok Lee, my father, Jong-Hyun You,  
and my husband Timothy Nam who believe in me.

## Mothering a Child With Autism in the United States and in South Korea

### INTRODUCTION

The values and norms of a society influence what mothering means (Glenn, 1994). To be considered “good,” women in the United States are expected to take care of their children, often sacrificing their own desires and interests for their children’s needs (Arendell, 2001; Hays, 1996). They also are expected to cultivate the talents of their children and socialize them to be successful in society (Lareau, 2002). These expectations are not so different for mothers who have children with disabilities. In addition, what these women are expected to do is uniquely related to their child’s disability in particular sociocultural, historical, and political contexts (Skinner & Weisner, 2007; Whyte & Ingstad, 1995). Because disability is viewed as an individual’s failure or incompetence in most societies (Whyte & Ingstad, 1995), mothers are expected to provide care and to manage the stigma and discrimination associated with their children’s disabilities (Green, 2003; Read, 2000; Traustadottir, 1991).

In this dissertation, I attend to the meanings of mothering a child with autism. In particular, I highlight how White American mothers and South Korean mothers who have children with autism understand themselves and their children. In the first manuscript, I pay attention to how White American mothers understand themselves and their children with autism through social interactions with family members, friends, and professionals. In the second manuscript, I concentrate on how mothers conform to and resist sociocultural systems that stigmatize individuals with disabilities

and devalue women's care work. By focusing on the narratives of these women, I expand the discussion of motherhood to embrace the experiences of mothers who provide care to their children with autism.

### A Description of the Studies

In the first study, *Striving to Be a Better Mother: Women Who Have Children with Autism*, with Lori McGraw and Katherine MacTavish, I examined the development of a maternal self-image by analyzing the stories of 12 middle-class, White mothers who have children with autism in Oregon. Using a qualitative research method, I conducted in-depth interviews with these women during the academic year of 2007-2008. Guided by symbolic interactionism and feminism, I focused on (a) how women who have children with autism understand themselves and their mothering and (b) how their ideas are shaped by their social interactions with relatives, friends, neighbors, and professionals. I paid attention to the ways that women exercise their agency through social processes.

In the second study, *The Intersection of Motherhood and Disability: Being a "Good" Korean Mother to an "Imperfect" Child*, with Lori McGraw, I investigated the intersection of gender and disability by analyzing the narratives of 14 middle-class, South Korean women who have children with autism. Using a qualitative research method, I conducted in-depth interviews with these women during the summer of 2006. Guided by feminist and disability theories within a social constructionist framework, I looked at (a) how dominant sociocultural systems related to mothering and disability shape South Korean mothers' understanding of themselves

and their children with autism and (b) how mothers conform to and resist these systems. I paid attention to both traditional and contemporary discourse on motherhood and children with disabilities in South Korea.

### Theoretical Perspectives

The studies in this dissertation are guided by unique but related theoretical perspectives. For the first study, symbolic interactionism and feminism guided the research process for investigating women's understandings of themselves and their children with autism. For the second study, the integration of feminist and disability theories within a social constructionist framework offered a way to examine how South Korean mothers conform to and resist discourse related to being a "good" mother and a "normal" child.

#### *Symbolic Interactionism*

Since Herbert Blumer (1969) invented the term *symbolic interactionism*, integrating thought from a number of theorists to form its foundation, symbolic interactionism has been influential in advancing the understanding of human beings (LaRossa & Reitzes, 1993). With attention to the relationship between symbols and interactions (Blumer, 1969; Erikson, 2003; LaRossa & Reitzes, 1993), symbolic interactionists focus on meanings that individuals create as they interact with others. During this interactive process, individuals develop understandings of themselves. In other words, they develop a self-concept through interaction with others. Their self-conceptions, in turn, affect their behaviors.

Symbolic interactionism has helped not only social scientists to understand human beings but also family scholars to recognize that family is a social institution (Erikson, 2003; LaRossa & Reitzes, 1993). According to LaRossa and Reitzes (1993), symbolic interactionism uniquely contributes to family studies because of “the emphasis it gives to the proposition that families are social groups and, its assertion that individuals develop both a concept of self and their identities through social interaction, enabling them to independently assess and assign value to their family activities”(p. 136). A symbolic interactionist theoretical perspective suggests that mothers understand themselves and their mothering a child with autism through interaction with their extended family members, friends, neighbors, and professionals.

#### *Social Constructionist Perspective*

Since Berger and Luckmann (1966) initiated a discussion about the nature of subjective and objective realities in their book *Social Construction of Reality: A Treatise in the Sociology of Knowledge*, social constructionism has provided an alternative worldview for social scientists studying diverse family relationships. The origins of social constructionism, however, can be traced back to symbolic interactionism (Gubrium & Holstein, 2000; Larkin, 2004). According to McGraw and Walker (2005), both social constructionists and symbolic interactionists are interested in how individuals understand themselves. Schwandt (2000) argues that with a social constructionist perspective, individuals take an active part in the interactive process of creating meanings; “We invent concepts, models, and schemes to make sense of experience, and we continually test and modify these constructions in the light of new



experiences (p. 197).” Social constructionists also focus on discourses within a specific culture (Burr, 2003). Discourses are made up of cultural and material practices that shape individuals’ understandings of themselves and their relationships in the world (Denzin, 1997; Schwandt, 2000).

To understand this interactive process of creating meanings, a careful examination of the existing knowledge about motherhood and disability is necessary (Burr, 2003; Roy, 2001). For instance, although a wheelchair can be described as a chair with two wheels, this physical description might have different meanings to different individuals. For individuals who are physically capable of walking without any assistance, a wheelchair might be a symbol of disability or of the inability to walk. For those who are physically incapable of walking, however, a wheelchair might be a symbol of mobility. Knowledge about a wheelchair is constructed through such subjective interpretations of a wheelchair.

In studying the meanings given to the experiences of mothers who have children with autism, a social constructionist theoretical perspective allows me to pay close attention to both (a) how sociocultural systems shape women’s understandings of themselves and their children and (b) how these women resist and/or conform to the dominant discourse related to mothering and disability.

*Feminist theories.* Feminist theories highlight discourses that encourage mothers but not fathers to be primary caregivers for their children with autism. Feminism has inspired social scientists to focus on altering unfair power relations between women and men both in and out of family contexts (Glenn, 1994; Osmond &

Thorne, 1993; Thompson & Walker, 1995; Tong, 1998). Within a patriarchal family structure, women, ironically, have been supported and suppressed (Ferree, 1990; Thompson & Walker, 1995). Feminist theories, then, enable me to pay attention to how mothering can simultaneously weaken and strengthen women's position in families and in the larger social world.

From a feminist perspective (Osmond & Thorne, 1993; Thompson & Walker, 1995; Weedon, 1997), the particular sociocultural context in which a woman lives influences how she understands herself. For example, sociocultural discourses that vary over time and place define and reinforce what it means to be a proper woman. Glenn (1994) argues that mothering is closely connected with gender, not because of women's biological characteristics, but because of stratification and hierarchy within a society that devalues women and children. Mothers who have children with autism play a major caregiving role not because they are biologically more suited for the job, but because they live in a society where the division of care work is hierarchical. Feminism provides a political and theoretical framework to discuss the sociocultural image of motherhood and to question the gendered care work in families of children with autism.

*Disability theories.* Disability theories and disability rights movements also provide a framework to understand the meanings of mothering a child with autism. Historically, individuals with disabilities have been called disabled, retarded, or crippled, terms that diminish their personhood and highlight their impairments (Murphy, 1995; Whyte & Ingstad, 1995). Today, because of disability activists, the

term, *individuals with disabilities*, is used to honor the social position of these individuals and to relegate their disabilities to a secondary status (Barnes, 1996).

Being considered “abnormal” or “bad” and “normal” or “good” is related to the values and norms of any given society and culture (Whyte & Ingstad, 1995). Although disability has been universally defined as “any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being” (World Health Organization, 1980, p. 28), the meanings of disability are specific to how it is viewed in any given society. Disability can be understood, then, not as a biological experience but as a sociocultural experience that limits and constrains, and perhaps supports and enables the lives of the affected individuals (Murphy, 1995; Whyte & Ingstad, 1995).

In conclusion, symbolic interactionist, social constructionist, feminist, and disability theoretical perspectives guided the research in this dissertation. These theories are unique, but related to one another in that individuals understand themselves within social context. For both studies, feminist theories offered a foundation to understand the socially undervalued care work that women perform (Osmond & Thorne, 1993; Thompson & Walker, 1995; Tong, 1998; Weedon, 1997). Both symbolic interactionist and social constructionist perspectives allowed me to pay attention to the meanings that women assign to their mothering experiences (Blumer, 1969; Gubrium & Holstein, 2000; LaRossa & Reitzes, 1993; Schwandt, 2000). In addition, disability theories helped me to notice how children with autism are viewed

in the Korean cultural context for the second study (Murphy, 1995; Whyte & Ingstad, 1995)

### Overall Literature Review

Women are expected to carry out the direct and indirect activities of providing care for children in both South Korea and in the United States (Coltrane, 2000; Hochschild & Machung, 1989; Lee & Keith, 1999; McGraw & Walker, 2004). Women in each country have been expected to intensively socialize their children as well (Cho, 1998; Hays, 1996; Lee & Keith, 1999). A good mother in each of these cultural contexts engages in activities that are “exclusive, wholly child centered, emotionally involving, and time-consuming,” thereby sacrificing her desires and time for her children’s needs (Arendell, 2001, p. 413).

Another similar pattern in these two countries is the stigma associated with individuals with disabilities. In both South Korea and in the United States, there is intentional and unintentional prejudice toward and discrimination against individuals with disabilities (Kim, 2002; Lee, 1998; Murphy, 1995). Mothers who have children with disabilities confront educational and social discrimination against their children when they seek educational opportunities for them. Being a good mother may not be enough for these women, however. Borrowing the term from Goffman (1963), they also may need to be “wise,” accepting and embracing their children’s abnormality and sharing the stigma experienced by their children.

Previous research on mothering and on mothering a child with disabilities has paid scarce attention to how these mothers experience and create meanings in relation

to the sociocultural images of good mothering (McDonnell, 1998; Pun, Ma, & Lai, 2004). Instead, most researchers from South Korea and the United States have focused on the physical, psychological, and financial stresses that mothers experience because of their children's disabilities (Lee & Jun, 2004; Leiter, Krauss, Anderson, & Wells, 2004; Litt, 2004; Porterfield, 2002).

*Gender and Mothering in the United States and South Korea*

In the United States, motherhood is an institution that encourages women to think and act in conformity with larger social and cultural expectations (Bernard, 1974; Osmond & Thorne, 1993). One of these expectations is that a woman will sacrifice her time and energy for her children (Hays, 1996; Thompson & Walker, 1989; Walzer, 2004). According to several scholars (Arendell, 2001; Glenn, 1994; Hays, 1996; Walzer, 2004), mothers organize and carry out activities that nurture others and strengthen family relationships. These activities range from hugging their children to scrubbing toilet bowls. Whatever the meanings given to such activities, mothers often perform a "second shift" of housework (Hochschild & Machung, 1989), childcare, and household management beyond paid work outside the home more than fathers do (Coltrane, 2000; Lareau, 2002; McGraw & Walker, 2004; Thompson & Walker, 1989).

An image of a good mother in South Korea is not so different from the image in America, although it is rooted in a different philosophical foundation. Confucian thought, one of the major belief systems in Korean society (Rhi, 1998), has played a significant role in reinforcing the gendered position of women in families (Cho, 1998; Lee, 1998). Confucianism promotes the understanding of human relationships through

the logic of the *Samkang-Oryun* (Three Bonds and Five Relationships) (Tu, 1998). For the purpose of social stability, the idea of *Samkang* (Three Bonds) is based on dominance and obedience. Historically, this idea appeared in the *Han fei tzu*, an original Confucian belief that was transformed into a political ideology: “The minister serves the king, the son serves the father, and the wife serves the husband. If the three are followed, the world will be in peace, if the three are violated, the world will be in chaos” (Tu, 1998, p. 122). *Oryun* (Five Relationships) (i.e., father and son, ruler and minister, husband and wife, young and old, and friend and friend) also provides guidelines for relationships. In a husband-wife relationship, for example, the principle of mutuality and the division of labor for accomplishing and maintaining family stability is emphasized. For the purpose of family harmony, the idea of *Samjong-jido* guided the lives of women (Cho, 1998). Within this principle, women must follow three men in their lives: fathers, husbands, and eldest sons. The virtue of womanhood in Confucianism is earned by being married to a man whom a woman follows, accepting a subservient family role, and bearing a son. Some of these principles have faded with modernization, but still continue to influence the lives of contemporary women.

These beliefs have both encouraged and hindered the lives of women in South Korea. Traditional Korean society has encouraged mothers to sacrifice their lives for their children, especially their sons (Cho, 1998; Kim, 1999). When a mother raises a successful son, then, usually when she becomes old, she achieves social respect, status, and power over other family members. The social status of women more so than men

is closely related to their role as mothers, regardless of their engagement in paid employment (Cho, 1998; Kim, 1993). After World War II, western influences (e.g., democracy, capitalism, and Christianity) aided the social mobility of working and poor families (Lee, 1998). Education, traditionally only available to privileged groups according to the caste system, became a stepping-stone for poor individuals and families to gain social and economic stability (Lee, 1998). Korean mothers have been expected to take responsibility for educating their children. In this way, children can achieve social and economic stability (Cho, 1998).

Mothering activities and practices are also closely linked to social, political, and historical contexts in the United States (Glenn, 1994). In the late 17<sup>th</sup> and 18<sup>th</sup> centuries, a major responsibility of a good mother was to breed a good line of children for economic purposes (Badinter, 1981). During the late 19<sup>th</sup> century, with the advent of the ideology of innocent childhood, mothers in middle-class families dedicated their lives to educating and socializing their children (Badinter, 1981; Wishy, 1968). Since the mid 20<sup>th</sup> century, the image of a good mother has been intensified among middle-class American families (Hulbert, 2003). Advice literature, written primarily by male child experts, highlights that mothers are essential for childrearing (Hays, 1996; Hulbert, 2003; Walzer, 2004). Many women have followed this advice and have felt valued for their mothering (Glenn, 1994). When mothers are not self-sacrificing and all-giving, however, they are targeted for criticism. Furthermore, mothers are expected to be professionally successful, meeting the sociocultural ideal of a *supermom* (Arendell, 2001).

*Mothering a Child With a Disability*

Previous studies often have focused on the stress parents who have children with disabilities feel because of their experiences (Bailey & Simeonsson, 1988; Beckman-Bell, 1981; Singer & Farkas, 1989). These studies also highlight what parents need to do to cope successfully with their situations. The studies have shown that parents who have children with disabilities do indeed have higher levels of stress compared to their counterparts whose children do not have disabilities (Bristol & Schopler, 1984). Parents also have more financial problems and marital difficulties (Beckman-Bell, 1981). Past studies also emphasize that parents experience a life long journey of caregiving that is accompanied by feelings of guilt, anger, devastation, and sadness (Blaska, 1998; Turnbull & Turnbull, 1997). Although findings from these studies have contributed to the understanding of families in such situations, a deficit-focused approach fails to notice that caregiving is also rewarding.

Moreover, the highly gendered nature of caregiving for children with disabilities has been overlooked (Traustadottir, 1991), despite the fact that fathers are less likely to be involved in direct and indirect care for their children (Marcenko & Meyers, 1991). Mothers spend more time and energy on family work than fathers do (Coltrane, 2000; McGraw & Walker, 2004; Thompson & Walker, 1989), particularly when they are providing care to their children with disabilities (Read, 2000; Traustadottir, 1991, 2000).

The experiences of mothers who have children with disabilities are contradictory and include both stresses and joys. Caring for children with disabilities



can be empowering for some mothers because this experience gives them a sense of satisfaction and pride (Nicholas, 1999; Traustadottir, 1991, 2000). These mothers can see themselves as being good (Skinner, Bailey, Correa, & Rodriguez, 1999). Two thirds of mothers with children who have developmental disabilities, for example, felt that they had become good mothers (Skinner et al., 1999). Caregiving can also be a troubling experience. Mothers can feel trapped and restricted by their responsibilities (Nicholas, 1999; Read, 2000; Traustadottir, 1991). In a study by Traustadottir (1991), caring meant “the caring work, which can be extremely hard and demanding” for the mothers she interviewed (p. 216).

Evidence suggests that mothers caring for children with disabilities also work to create a new kind of mothering image for themselves (Nelson, 2002). This process involves mediation, meaning that mothers interpret their children’s needs to professionals and even strangers (Read, 2000). They also make efforts to change the stereotypical image of individuals with disabilities by presenting a positive image of their children to friends, family, and others (Read, 2000). Advocating for the needs and rights of their own children and others with disabilities can become a part of their mothering as well (Traustadottir, 1991). Thus, for these women, being a good mother involves mediating the stigma that is associated with their children’s disabilities.

Beyond these experiences, several scholars have paid attention to how the sociocultural images of a good mother interact with mothering a child with a disability. In raising children who have disabilities, mothers often feel they are being blamed or labeled as bad (Landsman, 2000; McDonnell, 1998; McKeever & Miller, 2004; Read,

2000). An image of a good mother who bears and raises a healthy child who can be a productive member of society is strong in both South Korea and the United States. Sometimes, though, sociocultural ideas that serve to blame mothers for their children's imperfection can be transformed by mothers into blame for the neurological functioning of their children's brain (Singh, 2004). This is especially true for mothers whose children are diagnosed with Attention Deficit/Hyperactivity Disorder (Singh, 2004).

McKeever and Miller (2004), in their reanalysis of three qualitative studies, found that Canadian mothers of children with disabilities are under social pressure to conform to traditional ideas of mothering. Giving up or limiting their paid work hours is one strategy these women used to engage in this kind of mothering (Leiter, Krauss, Anderson, & Wells, 2004; McKeever & Miller, 2004; Porterfield, 2002). McKeever and Miller argued that these mothers played within the rules of the sociocultural ideologies of a good mother, but they also resisted the idea of a spoiled body image for their children with disabilities. These mothers tried to increase the social position of their children by paying extra attention to their children's hygiene and clothing.

#### *Mothering a Child With Autism*

Approximately 1.5 million Americans (0.005%) and 13,000 South Koreans (0.0002%) are diagnosed with autism spectrum disorders (United States Government Accountability Office, 2005; Korean Ministry of Health and Welfare, 2008). Because of the increasing prevalence of this disorder and the ambiguity of its cause (Newschaffer, Falb, & Gurney, 2005), ASDs have recently received great attention

from the general public in both South Korea and the United States. Over the last few years, several news magazines in both countries published articles about children with ASDs, focusing on its causes (Gorman, 2004; Kalb, Springen, Pierce, Raymond, & Hontz, 2005; Kim, 2005; Lee, 2005). These articles alerted both South Korean and American parents to watch for early signs of ASDs in their children. Reporters also warned that routine childhood shots such as the MMR--the triple vaccine against measles, mumps, and rubella—might cause children to develop ASDs.

Recently in South Korea, a nonfictional film was made about a young marathoner with ASDs and his persistent mother. This film received great attention from the general public, recording the highest box office rating in early 2005 and receiving a number of awards (Lee, 2005). In the United States, the Oscar winning film, “Rain Man,” casting Dustin Hoffman as a savant with autism has continued to influence how the general public thinks of individuals with autism (Bumiller, 2008). As more children are diagnosed with ASDs (Newschaffer, Falb, & Gurney, 2005), this particular disability draws considerable interest.

In both countries, ASDs have been one of the latest disabilities to be recognized. ASDs in the United States were included in the most recent American Psychological Association classification manual, *Diagnostic and Statistical Manual of Mental Disorders* 4<sup>th</sup> edition (Mauk, Reber, & Batshaw, 1997; Newschaffer, Falb, & Gurney, 2005). In South Korea, ASDs were classified as developmental disabilities in 1999 (Kim, 2005). ASDs are pervasive disorders that affect individuals’ information processing, integration, and organization abilities. These disorders are life-long

conditions that qualify as developmental disabilities. The severity of the condition varies greatly, from individuals who need someone else's assistance for almost everything they do to those who can function fairly independently. Overall, children and adults with ASDs have problems with social interaction, communication, daily functional skills, and educational performance (American Psychiatric Association, 1994; Mauk, Reber, & Batshaw, 1997). Unlike other developmental disabilities, the physical appearance of these children often does not differ from those of typically developing children. Moreover, about 80% of children with ASDs are boys (Mauk, Reber, & Batshaw, 1997). Though we know major characteristic of ASDs, further research is required to find out what causes this disability.

Leo Kanner, who first identified children with autism a half century ago, theorized that cold, obsessive, and mechanical mothering contributed to children developing autism (Kanner, 1943; Mauk, Reber, & Batshaw, 1997; McDonnell, 1998). In his theory, "refrigerator" mothers, who lack affection and warmth, produce children who cannot interact with others appropriately and exhibits odd behaviors, despite their healthy appearance. The relatively late onset of the disability (at about age three) also aided this theory. Unfortunately, such beliefs still exist in the United States. Mothers who have children with autism often feel blamed for not interacting enough with their young children, particularly if they have left their children in childcare in order to work for pay (McDonnell, 1998).

A more recent debate about whether routine childhood vaccinations may cause children to develop autism also may contribute to labeling mothers with children with

autism as “bad.” Women are blamed for having their children immunized and for not having them immunized. Although there are not any known causes for autism (Mauk, Reber, & Batshaw, 1997; United States Government Accountability Office, 2005), mothers of children with autism may feel guilty about their children’s disabilities because of what they have or have not done.

Similar to previous studies about caring for children with disabilities, researchers focusing on children with autism are concerned about parental or maternal stress and their associated coping strategies (Bristol & Schopler, 1984; Gray, 1994, Honey, Hasting, & McConachie, 2005). Most studies show that parents or mothers experience psychological and physical stress when caring for their children with autism, despite their children’s healthy physical appearance (Bristol & Schopler, 1984; Gray, 1993, 1994; O’Brien, 2007). In his qualitative study of 33 parents of children with autism, Gray (1994) identified the sources of stress as being related to the characteristics of autism: (a) limited language development, (b) physically and/or sexually aggressive behaviors, and (c) developmentally inappropriate eating and toileting skills. Bristol and Schopler (1984) argued that the mothers of children with autism had an especially difficult time accepting their children’s diagnosis because the children exhibited some age or developmentally appropriate behaviors and they did not look sick or disabled. Because of this ambiguous nature of autism, O’Brien (2007) showed that the experience of receiving the diagnosis of autism is similar to the experience of ambiguous loss that was positively related to higher level of perceived stress and depressive symptoms in her mixed methods study of 63 mothers who have

children with autism.

Although these studies have made valuable contributions to understanding the experiences of parents who have children with autism, most of them fail to recognize that caregiving is gendered (Traustadottir, 1991). Even a study about gender and caring for a child with autism missed that caring for children with disabilities is highly gendered work. Although Gray (2003) showed differences in the lives of mothers and fathers with children who had high functioning autism, he did not fully investigate what might have contributed to the differences. In comparing the experiences of mothers and fathers, it was clear that fathers saw themselves as sources of support to their wives, and their careers were not affected. Alternatively, mothers were direct caregivers for their children with autism, experiencing more stress than fathers. These women also reduced their paid work hours or quit their job altogether to care for their children.

McDonnell (1998) investigated the issue of mothering a child with autism more critically than Gary (2003). Her focus, however, was on the analysis of previous literature that has shown the sociocultural view of motherhood and autism. Overall, no empirical studies about mothering a child with autism have been conducted on sociocultural ideologies of motherhood and disability in both South Korea and the United States.

#### Rationale and Research Questions for the Present Studies

The review of literature suggests that there is no empirical study that focuses on how women understand themselves and their children with autism highlighting

how both gender and disability are sociocultural constructs that shape what it means to be a mother with a child who has a disability. This is true for research conducted in both the United States and in South Korea. Understanding the social construction of gender and disability, though, is particularly important because mothering a child with autism is closely related to the sociocultural contexts that perpetuate negative ideas about individuals with disabilities and hold women responsible for the problems of their children.

The main goal of this dissertation, therefore, is to expand the understanding of mothering a child with autism. To achieve this goal, I paid attention to the meanings women gave to their experiences in relation to sociocultural processes regarding gender and disability in two distinct cultural contexts. The overarching research question asks how sociocultural ideas about mothering and disability, particularly autism, shape White American and South Korean mothers' understanding of themselves and their children with disabilities. For the first study, I examined (a) how middle-class, White women who have children with autism understand themselves and their mothering and (b) how their ideas are shaped via their social interactions with relatives, friends, neighbors, and professionals. For the second study, I asked (a) how dominant sociocultural systems related to mothering and disability shape South Korean mothers' understanding of themselves and their children with autism and (b) how mothers conform to and resist these systems.

## Method

A social constructionist theoretical framework along with symbolic

interactionist, feminist, and disability theories provided guidance for this dissertation. First, I discuss the theoretical perspectives that influenced the methodological approach. Then, I describe the methodological approach, sampling method, characteristics of participants, interview processes, and data analysis.

A social constructionist perspective allowed me to critically review what has been understood as true (Burr, 2003). Rejecting a naturalistic interpretation of the world, I emphasized that knowledge is constructed through subjective interpretations of the world (Burr, 2003; Roy, 2001). A social constructionist approach also recognizes that both researchers and participants actively engage in the construction of knowledge through a reflective process (Allen, 2001; Fox & Murry, 2000). According to McGraw, Zvonkovic, and Walker (2000), *reflexivity* is “a process whereby researchers place themselves and their practices under scrutiny, acknowledging the ethical dilemmas that permeate the research process and impinge on the creation of knowledge (p.68).” This definition helped me to reflect on my position as a Korean researcher who is married to a Korean American man in this dissertation. I also considered how my position as a middle-class, childless woman would influence my interviews with women and the analysis of the stories of women in the United States and South Korea.

Considering the theoretical frameworks, relevant literature, and the research questions, a qualitative research approach was appropriate for the studies in this dissertation (Berg, 1998). Qualitative research is an inquiry process that provides a way to understand the meanings individuals give to their experiences (Creswell, 2003;



Denzin & Lincoln, 2000; Gilgun, 1992). A qualitative research design also allows the researcher to emphasize that reality is constructed within specific social contexts (Denzin & Lincoln, 2000).

To obtain rich information on the meanings mothers give to their experiences in the United States and South Korea, I used a purposeful sampling method (Patton, 2002). This sampling method allows researchers to gain insight into a phenomenon (Patton, 2002). Participants were selected on the basis of their potential for providing an in-depth understanding of mothering a child with autism. Except for their nationality, participants in the two studies shared similar characteristics: (a) having a child (age five to nine years old) with a moderate level of autism, (b) being married to the biological father of the child with autism, (c) having at least an Associate's degree, (d) residing in an urban area, and (e) being in a professional or managerial position or being in a relationship with someone who is in a professional or managerial position. These criteria were particularly relevant because maternal experiences vary depending on the type and severity of a child's disability (Gary, 1993, 1994) and they are influenced by socioeconomic status, family structure, and geographic location (Collins, 1994).

Professionals who directly or indirectly work with families who have children with autism assisted me by distributing the information about the study to mothers who have children with moderate level of autism. Interested mothers provided their contact information to the professionals or sent me a pre-stamped postcard indicating their interest in participating. I then telephoned the women to screen them for their eligibility described above. For the first study, local school districts and parent support groups

assisted the recruitment process for White, Non-Hispanic women in the United States who have children with autism. I selected only White mothers because race and ethnicity influence maternal experiences (Collins, 1994). For the second study, the Korea Institute for Special Education (KISE), special education schools, treatment centers, and inclusive childcare centers assisted with the recruitment process.

Using a qualitative research approach, I conducted in-depth interviews with participants in the United States and South Korea. For them to feel comfortable in their natural settings, I asked mothers to choose their preferred place for interviews. Interview questions were loosely structured, focusing on the ways mothers of children with autism understand their experiences in relation to discourses on motherhood and disability, more specifically autism. Each participant spent approximately two to two and a half hours talking about her life. Participating mothers received a \$10 gift certificate as a symbol of my gratitude for their time and effort. After the interview, mothers were asked to nominate other mothers who might be interested in the study. All interviews were tape-recorded and transcribed verbatim. For the second study, all interviews were translated into English.

In collaboration with co-authors, I identified patterns that inductively emerged from the data. From these patterns, I developed distinct concepts and themes relevant to the experiences of mothers within each sociocultural context. The data analysis process was aided by the strategies of grounded theory such as memoing, drawing diagrams, and clustering concepts (Charmaz, 2006). Using *reflexivity* (McGraw, Zvonkovic, & Walker, 2000), I also paid attention to my position as a married,

childless woman emigrated from South Korea during data collection and through the writing phase. In the following sections, I present the two manuscripts examining the meanings of mothering a child with autism: One regarding U.S. mothers and the other South Korean mothers.

STRIVING TO BE A BETTER MOTHER:  
WOMEN WHO HAVE CHILDREN WITH AUTISM

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### Abstract

Guided by symbolic interactionism and feminism, we qualitatively examined (a) how middle-class, White women who have children with autism understand themselves as mothers and (b) how their ideas are shaped by social interactions with others. Through in-depth interviews with 12 women who have children with autism, we found that these mothers understand themselves to be empathic supporters, mediators, and advocates for their children with autism. Their stories are shaped by selective attention to those who support their self-image and a disregard of those who undermine it. Implications for policy and practice are offered.

Feminist scholars have argued for a more complex understanding of the nature of motherhood by “focusing not just on the way women are oppressed as mothers, but on the way they act to assert their own standards of mothering” (Glenn, 1994, p. 18). This paper focuses on the ways that women who have children with autism are agentic in their roles as mothers. Though we highlight women’s agency, we do so with an understanding of the ways that women are oppressed by their care responsibility (Read, 2000; Traustadottir, 1991). Women are weighted down by motherhood because sociocultural belief systems encourage women to think of themselves as naturally suited for care work. Through this belief system, mothers are encouraged to place their children’s needs before their own needs (Skinner & Weisner, 2007; Read, 2000; Traustadottir, 1991). Having a child with a disability can be even more limiting to mothers because of the special needs of their children (Leiter, Krauss, Anderson, & Wells, 2004). In this sociocultural system, women learn to think of themselves as good when they devote their lives to their children with disabilities (Nicholas, 1999; Skinner, Bailey, Correa, & Rodriguez, 1999). Many of these women come to recognize their care work as a way to gain social recognition and a sense of accomplishment (Read, 2000; Traustadottir, 1991).

In this paper, we aim to answer two main questions: (a) How do middle-class, White women who have children with autism understand themselves as mothers and; (b) How are their ideas shaped by social interactions with others? We begin our paper by describing the literature on mothers who have children with disabilities. Then, we detail our qualitative study and discuss implications for policy and practice.

## Literature Review

Researchers have focused extensively on cultural beliefs that surround motherhood (Arendell, 2001). For a woman to be considered a “good mother,” she must sacrifice her time and energy for her child (Hays, 1996; Thompson & Walker, 1989; Walzer, 2004). Beliefs about motherhood are intertwined with beliefs about childhood (Badinter, 1981; Wishy, 1968). Middle-class children have been conceptualized over time as individuals who are innocent and in need of protection from the larger world (Coltrane, 2000). Middle-class women, then, are charged with the responsibility of protecting their children. Middle-class children are also thought of as a group who needs intensive education and support to develop their full potential in adulthood. Mothers, in turn, are expected to intensively socialize their children and cultivate their talents (Hays, 1996; Lareau, 2003). To nurture their children, mothers must engage in activities that are “exclusive, wholly child centered, emotionally involving, and time-consuming” (Arendell, 2001, p. 413).

The same sociocultural expectations applied to mothers in general are also applied to mothers who have children with disabilities. These mothers are expected to love their children regardless of their disabilities. They also are expected to provide medically and educationally appropriate care for their children’s special needs. The demands of this care often leave mothers feeling constrained by their responsibilities (Nicholas, 1999; Read, 2000; Singer & Farkas, 1989; Traustadottir, 1991). They show more depressive symptoms and they experience more stress than similarly situated mothers with typically developing children (Bailey & Simeonsson, 1988; Beckman-

Bell, 1981; Goldberg, Morris, Simmons, Fowler, & Levison, 1990).

In contrast, previous studies show that mothers with children with disabilities experience a sense of fulfillment when they master the skills necessary to provide care for their medically fragile children (Nicholas, 1999; Singer & Farkas, 1989). For example, Latina mothers with children who have disabilities perceived their mothering experiences as transformative of their lives (Skinner, Bailey, Correa, & Rodriguez, 1999). Mothers of children with disabilities develop positive self-images by becoming allies with their children and by negotiating positive interpretations of their children with professionals (Nelson, 2002; Read, 2000). Some mothers extend their care work to advocate for the rights of all children with disabilities (Read, 2000; Traustadottir, 1991). In this way, mothers are agentic in their resistance to a larger social order that stigmatize children with disabilities.

Women who have children with autism have experiences that are similar to women who have children with other types of disabilities. Their experiences are unique as well (Gray, 1993, 1994; Mauk, Reber, & Batshaw, 1997; O'Brien, 2007). Mothers of children with autism often feel a sense of ambiguous loss because it is difficult to diagnose children with autism, particularly when the child is very young (O'Brien, 2007). Children with autism often look healthy and their developmental delays vary (Bristol & Schopler, 1984; Mauk, Reber, & Batshaw, 1997). Consequently, Bristol and Schopler (1984) argue that mothers of children with autism struggle to accept their children's diagnosis. The cause of autism is not fully understood. Mothers must wade through a variety of contradictory information to determine what the best



course of treatment is for their children. Sometimes, they doubt their decisions. For example, some mothers believe that their children's autism was caused by immunizations they allowed their children to have (Newschaffer, Falb, & Gurney, 2005). Without a full explanation of the cause of autism (Newschaffer, Falb, & Gurney, 2005), mothers feel responsible for their children's disabilities (Read, 2000).

These studies have broadened our knowledge of mothers who have children with autism. Scarce attention has been paid, however, to the ways that these women negotiate their identity as mothers via social interactions with others.

### *Theoretical Framework*

To understand how middle-class, White women who have children with autism understand themselves as mothers, we used feminist and symbolic interactionist theoretical perspectives. Symbolic interactionism provides a framework to investigate the creative process women use to develop a maternal identity (Erikson, 2003; LaRossa & Reitzes, 1993). For example, research has shown that first-time mothers begin to develop a maternal identity during their pregnancy. At this time, they imagine the kind of mother that they will become (Miller, 2007). This identity is revised through interactions with their actual child and with others in their social world (Arendell, 2001; Glenn, 1994; Marshall, Godfrey, & Renfrew, 2007). The focus of this study is on how women develop and modify their maternal role as they interact with their child and close others (Blumer, 1969; LaRossa & Reitzes, 1993).

### *Method*

Our study was part of a larger cross-cultural research project that examines

discourse on gender and disability in South Korea and in the United States. The present analysis focuses on the data collected from mothers in the United States. To investigate how women understand mothering a child with autism, we interviewed 12 middle-class, White women. We focused on two main questions: (a) how do middle-class women who have children with autism understand their mothering role? and (b) how are their ideas shaped via social interaction with others? A qualitative research approach offered the best way to examine the meaning-making processes of the women in our sample (Creswell, 2003; Denzin & Lincoln, 2000).

### *Sampling*

Using a purposeful sampling method (Patton, 2002), we intentionally pursued a narrowly defined sample because women's understandings of themselves are intertwined with their social environment (Collins, 1994). Therefore, we limited our sample by disability, socioeconomic status, family structure, geographic location, and racial/ethnic background. First, we sought mothers who have young children with autism. Because maternal experiences vary depending on the level of a child's autism (Gary, 1994), we focused on mothers of children with moderate communicative and social dysfunctions. Additionally, we recruited mothers whose children had been diagnosed with autism several years earlier. In this way, these mothers were not adjusting to new information about their children's disabilities. We limited our sample to mothers whose children were between the ages of five and nine years old.

We asked special education professionals and parent support group leaders to distribute a total of 90 research packets to potential participants in Oregon. A total of

28 mothers responded to our request by sending a pre-stamped letter of interest back to us. The first author then telephoned interested women to determine if additional eligibility criteria were met: (a) Being a White American, (b) currently married to the biological father of her child with autism, (c) residing in an urban setting, (d) having at least an Associate's Degree, and (e) having a professional or managerial position or having a husband who is in a professional or managerial position. Our final sample consisted of middle-class, married White mothers who reside in an urban setting and who have a child with a moderate level of autism.

### *Participants*

Twelve out of the fourteen women who showed interested in the study met the additional criteria and agreed to participate in the study. Three mothers had Associate Degrees, 8 mothers had Bachelors' Degrees, and 1 mother had a Masters' Degree. Eight mothers were employed: 3 full-time, 3 self-employed, and 2 part-time. All of the fathers were employed full-time except for one who recently quit working due to his own disability. Household incomes were around or above the national median household income of \$48,451 (<http://www.census.gov/>). The women were ranged in age from 30 to 51 years ( $M = 39$ ), and their children were, on average, 7 years of age in range of age 6 to 9 years. The children with autism in our study included more boys ( $n = 11$ ) than girls ( $n = 1$ ).

### *Interviews*

The first author conducted in-depth interviews with each mother. Interviews were loosely structured (Patton, 2002). Each interview took place in a location of the

mother's choosing. Half of the women in our study preferred to be interviewed at their homes and the others chose local coffee shops or restaurants. During the interviews, mothers were encouraged to tell stories about their children with autism and themselves. We began the interviews by asking mothers about the birth stories of their children with autism and progressed to questions about their present lives. We also asked them to discuss their ideas about motherhood in general and about mothering a child with autism specifically. Some example questions are, "What does being a good mother mean to you?" and "How has having a child with autism influenced your view of what makes a good or bad mother?" We also asked "What do you think that your relatives think makes a good mother to a child with a disability? How do these ideas influence your view of your own mothering, if at all?" These questions served to encourage the mothers to talk about their experiences with extended family members, friends, neighbors, and professionals. Interviews lasted an average of two hours each. Mothers received a \$10 gift certificate as a gesture of our gratitude for their time and effort in the study. All interviews were tape-recorded and transcribed verbatim. In order to ensure confidentiality of participants and their children, pseudonyms have been used in this paper.

### *Data Analysis Process*

Our data analysis began with our choice of theory, with the questions we constructed, and with the way we wrote about our findings (Denzin & Lincoln, 2000). Using symbolic interactionist and feminist theoretical perspectives, we examined middle-class, White women's narratives to conceptualize how they understand

themselves as mothers and how their ideas are shaped by social interactions with close others. During the *initial coding* phase (Lofland & Lofland, 1995; Charmaz, 2006), we identified codes such as acceptance, patience, and advocacy. We also paid attention to supportive and unsupportive interactions the women had with family members, friends, and professionals. We attended to how they described themselves interacting with others in relation to their children with autism. During the *focused coding* phase, we concentrated on concepts that appeared more frequently (Lofland & Lofland, 1995) and we sought relationships among these codes. Finally, we developed primary themes and patterns that are discussed below.

### Themes

We found that middle-class mothers who have children with autism understand themselves as empathic supporters, mediators, and advocates for their children with autism. Their stories are shaped by selective attention to those who support their self-image and a disregard of those who undermine it.

#### *Empathic Supporter: “Patience Makes a Good Mother”*

All 12 women in our study understood themselves as striving to be better mothers to their children with autism. They stated that being a better mother began with their acceptance of their children with disabilities. They shared the idea that acceptance of their children was the primary determinant of whether they were to be considered “good” or “bad” mothers. When asked what makes a good mother, Joanne stressed “accepting [children] for who they are.” Debbie similarly explained: “I think a

lot of it is accepting that your child is who he is.” Mary reflected on the process: “You just have to work through it until you get to the point of acceptance.”

Although these mothers were careful not to be judgmental about other mothers, they explained that when mothers denied their children’s diagnosis they were, in fact, rejecting their children. According to them, women could be perceived as bad mothers if they were unaware of the needs of their children and were unwilling to seek appropriate educational and medical treatments for their children. Joanne discussed her idea of a bad mother: “I think someone who doesn’t recognize the special needs of their child, or care about them, or is in denial.” Sheila stated her opinion: “I’ve seen some pretty bad autism mothers. I would think not knowing the facts about what your kid has. That’s what really pains me.” Debbie stated: “If you’re still in denial, I don’t think you’ll be a good parent.”

Four of the mothers explained that receiving information that their child had autism reassured them that they were not bad mothers. Instead of attributing their children’s strange behavior to their own incapacity to raise children, they could attribute the behaviors to a disability. For these women, the diagnosis provided a sensible explanation for why their children were different. Prior to receiving a diagnosis of autism, Erica said that she questioned her mothering ability: “I thought, ‘Maybe I’m an innately bad parent.’” Sheila noted: “I was really relieved because we were being judged.” Michelle explained: “It was a weird thing for me to get closure. He has autism. I was thinking ‘This is what I thought it was for a long time.’”

In order to raise their children with autism well, half of the women in our study explained that they needed extra patience to be a good mother. Joanne stated: “I often wish I were a better mother. I need to be more patient.” Teresa agreed: “I wish I was a little bit more patient.” Mindy said: “People have always told me I am very patient.” She continued: “That’s been even more important now.” Jane discussed: “If I lose my temper, it might have a bigger effect on my child with autism than if I lost my patience with another one.” Kerry stated: “Patience makes a good mother.”

To support their belief that they were accepting and patient mothers, women in our sample attended to reassuring comments from others. Karen stated: “My relatives have really validated my mothering.” Mindy described her extended family members’ comments: “My relatives say, ‘It’s great that you take him to music lessons. It’s great that you take him to soccer.’” Erica stated that her relatives thought highly of her patience: “All of my relatives have said, ‘Oh, thank God, you are her mother.’” Debbie appreciated the support she received from her in-laws: “It gives me positive reinforcement for the job that I am doing.”

Seven mothers focused on comments that highlighted the progress that their children had made. According to these mothers, their extended family members attributed their children’s success to them. Michelle remembered a compliment: “My brother said, ‘I don’t think Tyler would be as good as he is if he didn’t have you for a mother.’” Mindy talked about her extended family members, who only see her child once or twice a year: “They see huge differences in him. So [they say], ‘Whatever

you're doing, keep it up.” Jane felt good about herself when her relatives commented: “Wow, he is really doing good. You guys are doing a good job with him.”

Eight women maintained positive self-images by attending to affirming comments from professionals. The mothers believed that these comments motivated them to try harder to be good mothers. Joanne stated: “My son’s teacher thinks I’m doing a great job.” Michelle described her visit to a new doctor: “I was making [my son] laugh and playing with him and playing with some toys with him. The doctor said, ‘You’re really good with him. You really understand him.’” Teresa talked about a meeting she had with her child’s teachers: “They said, ‘See, that’s what makes a good mom—someone who understands the needs of her child.’ So, those comments make me feel good.”

Not everyone acknowledged the effort mothers make on behalf of their children with autism. Ten of the mothers told of times when strangers criticized their efforts. When they were criticized, a few mothers explained to these strangers that their children had autism and that was why their behavior was different. Most women, however, ignored the comments of strangers. Mary explained: “People tend to jump to conclusions. ‘Look at them. They are letting their children get by with it.’” Her response was to just “ignore it.” Jane’s response was similar: “Lots of people look at me like ‘What’s that kid’s problem?’ which I just try to ignore.” Sheila agreed: “A few years ago, [I] would’ve been compelled to explain it. Now, I just don’t.”

*Mediator: “I Have Introduced Them to Autism”*



The women in our study described themselves as mediators. Through their stories they relayed the idea that a mediator is someone who can act as a conduit through which broader understanding and acceptance of children with autism can occur. They explained that their role as a mediator was not easy because a lot of misinformation about autism existed. Eleven women stated, for example, that some of their extended family members initially did not understand how autism affected their children. These relatives thought that the children would “grow out of” their behaviors. When Michelle told her mother about her son’s autism, her mother responded: “Well, he’ll grow out of this, won’t he?” Other relatives did not take the diagnosis of autism seriously. Erica explained: “They kept saying, ‘Oh, no, she can’t possibly be autistic.’” Sheila described her father-in-law’s attitude about her son’s behavior: “He’s a little touched. It’s no big deal, why would he need all of this help?” Several mothers mentioned that their relatives thought that their children were spoiled. For example, Mary’s brother said: “Christopher is just a brat and that’s about it.”

The women indicated that they educated their relatives about their children with autism, particularly to explain how autism varies in severity across children. Erica confirmed to her relatives who were not so sure that her daughter has autism: “She is definitely autistic. I am trusting teachers’ experiences. The doctors were like ‘She is definitely under the umbrella somewhere.’” Michelle offered this account to her relatives: “He is like a typical boy. He’s just not comfortable with everybody.” Kerry clarified to her father who believed that his grandson would grow out of autism:

“He is not gonna grow out of it.” Teresa highlighted how she educated her parents and her in-laws: “If we find an article on autism, we share it with them.”

Eight women in our study also discussed negative interactions with their friends and neighbors who did not understand the special needs of children with autism. These interactions required the mothers to clarify the symptoms of their children’s disability. When a friend thought that autism was temporary condition, Jane explained: “No, they don’t grow out of it. They learn their life skills so they can progress, but he is gonna have it for the rest of his life.” Teresa acknowledged: “I have introduced my friends to autism because they just didn’t know what it was.”

When friends and family members could not accept their children with autism, mothers discontinued these ties. Sheila offered the following example: “We have friends that are not friends anymore.” She further explained that her father-in-law “rejected [her son] completely and only paid attention to her daughter.” She stated: “He’s not invited back. We’ve had to give up some relatives. He’s not invited to our house ever again.”

In contrast, mothers maintained ties with those who accepted their children with autism. These accepting individuals often knew of someone else with a disability. Karen, whose husband was recently diagnosed with Asperger’s syndrome, mentioned that she has a special connection with her mother-in-law. She stated, “My mother-in-law and I are very close. I usually call her first when something happens because she raised a child with autism without knowing it. It’s a special relationship that she and I have.” Teresa talked about her parents who adopted her sister with Down syndrome:

“They understand autism and they understand what it is like raising a child with a disability.” According to Debbie “All of my friends were accepting.” Joanne said: “Friends of mine are like ‘Oh! It’s not a big deal.’” Sheila appreciated having neighbors who accepted her son: “The people across the street babysit a little girl with William’s Syndrome. They totally get it.”

*Advocate: “Going Outside of Your Comfort Zone”*

Some of the women in our sample extended their mothering role to include advocacy for their own as well as other children with autism. Seven mothers discussed, for example, how they learned to voice their concerns to medical professionals. They explained that when they drew their pediatrician’s attention to their children’s slow language acquisition, they were ignored. Their pediatricians responded by saying, “let’s wait and see.” These physicians put off making referrals to professionals who could better understand their children’s developmental delays. Karen recalled asking for an evaluation of her son’s hearing. Instead of arranging for the hearing test, the pediatrician told her: “He won’t like [getting tested].” When Joanne discussed her son’s hand twisting and flapping behaviors, the pediatrician stated: “Oh, he’s just excited.” Cory had a similar experience. When she took her two-year-old son to the doctor because he was not speaking, the doctor said: “I think he is a thinker. I can tell he is really thinking.” Jane, talked about how her son’s pediatrician discredited her childrearing ability:

The doctor said to me, ‘Just read him more books and come back when he’s three.’ I thought, ‘Is she, stupid?’ I told her the problem. I’m a teacher. I know how I’m supposed to be reading a book to my child.

Instead of acquiescing to the opinion of their pediatricians, these mothers sought a second opinion. They wanted a better explanation of their children's behaviors and they wanted validation of their concerns. Karen talked about her decision to find a different pediatrician for her son: "I changed doctors because that's not the right answer for me." Michelle explained: "I took him to an occupational therapist and a speech guy to have him evaluated." Another mother, Jane, stated that she "went to a different doctor," and he said, "Okay, we'll do a referral to early intervention."

One mother confronted teachers in her child's school district about inappropriate treatment she believed her son was receiving. Karen explained that she demanded that her son be released from a locked three-by-five cell called the quiet room. Her son spent two to five hours a day in this room. She said: "When I saw where my son was spending a large part of his day, I felt like he was being mentally tortured." The teachers believed that the quiet room was their best behavior management option. Karen made it clear, however, that the treatment that her son received was inhumane.

According to five mothers, their identity expanded to include advocacy for the larger group of children with autism. These mothers explained that they worked to educate the larger community about children with autism. Two of these women were leaders of local support groups for families who have children with disabilities. Karen believed that an essential characteristic of a good mother is someone who is willing "to go outside her comfort zone to advocate for her child" and is "ready to go to battle."

Kerry said that activist mothers are good mothers because they “fight for the rights of their children. They are the squeaky wheels.” Erica agreed: “I want to become an advocate and help more people understand what [autism] is.” Michelle stated: “Now, anywhere I go, I tell people ‘My son has autism.’ It was a matter of pride.”

Six mothers pointed out that their ties to other mothers who have children with autism helped them to be more vocal about their children’s needs. Four of them were closely connected to support groups for parents who have children with disabilities. Jane explained the benefits of the group: “It’s nice to know other moms going through the same thing you are. I think that’s the greatest thing you can have. Then you don’t feel all alone.” Karen explained: “I could say almost all of my friends are other mothers with children with autism. It’s a community that I built.” Through the support they received in the group, Jane and Karen learned new ways to interact with others in public. Jane stated: “If someone ever says anything to me, I can hand them a card that tells them about autism.” Karen agreed: “Now I have little cards that I hand them.” Michelle summarized her relationships with other mothers who have children with autism in this way: “I think we always cheerlead for each other.”

### Discussion

The stories these mothers shared illustrate how mothers who have children with autism may think about themselves. They highlighted that they are empathic supporters, mediators, and advocates for their children with autism. Their images of themselves were constructed through their daily interactions with others. As empathic supporters, they indicated that they worked to accept their children and they tried hard

to be patient with their unique characteristics. To support their belief that they were accepting and patient mothers, women in our sample attended to reassuring comments from family members, friends, and professionals. For those individuals that were unsupportive of their identities as competent mothers, the women explained that they ignored the comments of these individuals. The mothers told stories that indicate that they served as a mediator between their children and those around them as well. As a mediator, they educated others about their children with autism. During the mediation process, mothers were selective about who they allowed into their lives. When friends and family members could not accept their children with autism, mothers discontinued their ties with these individuals. Advocating for their children with autism was an important aspect of these mothers' identities too. Some mothers depended on formal support groups to bolster their advocacy work.

Our findings are similar to other studies that highlight the challenges that mothers have raising children with autism. The literature suggests, for example, that mothers have a difficult time accepting the diagnosis of their children with autism (Gary, 1993; O'Brien, 2007) and they sometimes serve as advocates for children with disabilities (Read, 2000; Traustadottir, 1991). Our study enhances the empirical base of information on children with autism by focusing on the selective social processes that women engage in to make sense of their maternal self.

Because our sample consists of a small number of women who share similarities in that they are White, middle-class and live in an urban setting, generalizing our findings to all mothers who have children with autism in the United

States would not be appropriate. However, our study provides a first step toward understanding how women are agentic in their roles as mothers to children with autism and how they can be better supported by family life educators. Our findings support, for instance, the further implementation of a policy proposed by the American Academy of Pediatrics (<http://www.aap.org/publiced/autismtoolkit.cfm>). The American Academy of Pediatrics recognizes the importance of early identification of autism in young children. A recent survey, however, has shown that only 8% of pediatricians routinely screen for autism in their young patients (Johnson & Meyers, 2007). This number is alarming given the rise in the rate of autism in the United States (Mauk, Reber, & Batshaw, 1997). Training that incorporates the importance of listening to mothers' concerns would be one way that family professionals could contribute to this conversation.

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THE INTERSECTION OF MOTHERHOOD AND DISABILITY:  
BEING A “GOOD” KOREAN MOTHER TO AN “IMPERFECT” CHILD

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### Abstract

Integrating feminist and disability theories within a social constructionist framework, we asked (a) how dominant sociocultural systems related to mothering and disability shape South Korean mothers' understanding of themselves and their children with autism and (b) how mothers conform to and resist these systems. To answer these questions, we conducted in-depth interviews with 14 middle-class, South Korean mothers with children who have autism. We found that these mothers resisted stigmatizing attitudes toward themselves and their children and reconstructed the meaning of "normal" childhood by relying on a network of similarly situated mothers. They described themselves as "good" by adhering to Confucian family values that encourage women to sacrifice themselves to focus on their children's success. From these findings, we offer implications for practice.

Since Sociologist Ann Oakley rejected the belief “that all women need to be mothers, that all mothers need their children, and that all children need their mothers” (1970, p.186), scholars have become increasingly aware of motherhood as a socially constructed rather than a biologically determined phenomenon (Glenn, 1994).

Researchers also have shifted their view of disability away from a medical model toward a perspective that highlights the social processes that shape the experiences of individuals with disabilities (Whyte & Ingstad, 1995). How gender and disability are experienced, these researchers argue, is shaped by symbolic and material practices that evolve over time within particular historical and political contexts (Skinner & Weisner, 2007; Smith, 2003).

In this paper, we examine sociocultural beliefs about motherhood and disability in South Korea. We aim to answer two main questions: (a) How do sociocultural systems related to mothering and disability, particularly autism spectrum disorders, shape South Korean mothers’ understanding of themselves and their children with disabilities; and (b) How do these mothers resist and/or conform to dominant discourse about being a “good” mother and a “normal” child? We begin our paper by describing the sociocultural contexts within which South Korean mothers and their children with disabilities live. Then, we provide a summary of empirical evidence related to mothering a child with disabilities. Finally, we detail our qualitative study and provide evidence for how South Korean mothers understand themselves and their children with autism within this milieu.

#### Gender and Disability in South Korea

The lives of South Korean women have long been influenced by the Confucian way of understanding social ties. Through *Samkang-Oryun*, or the *Three Bonds and Five Relationships*, Confucianism provides Koreans with a framework that structures relationships between men and women and between families and the larger society (Lee, 1998; Tu, 1998). To encourage social stability and discourage change, the idea of *Samkang*, or the *Three Bonds*, emphasizes dominance of the king over the minister, the father over the son, and the husband over the wife. Those in a subservient position are encouraged to be obedient to those in a dominant position. *Oryun*, or *Five Relationships*, also provides guidance on appropriate social interactions. In husband-wife relationships, for example, a clear division of labor is considered ideal because Confucian thought argues that separate spheres for men and women will promote family stability. Finally, to encourage family harmony, the idea of *Samjongjido*, or the *Three Principles*, guides women's lives (Cho, 1998). These principles dictate that a woman must follow three men over the course of her life: Early in her life she follows her father, in adulthood she follows her husband, and in later life she follows her eldest son. Though Confucian influence has faded somewhat with modernity, these beliefs continue to influence the lives of Korean women (Cho, 1998; Yang & Rosenblatt, 2008).

Confucianism influences South Korean women's daily lives in that mothers but not fathers are expected to sacrifice their lives for their children (Cho, 1998; Kim & Ryu, 1996). Korean women are not evaluated by their own professional accomplishments, but by their children's achievements (Kim & Ryu, 1996). Thus, Korean mothers carefully manage the academic success of their children to ensure their own and their children's

social status (Cho, 1998). In an effort to promote their children's academic success, South Korean mothers commonly hire tutors and enroll their children in educational after-school programs (Hur & Yoon, 1998). When a mother raises a successful child, she achieves social respect, status, and power. The social status of women is closely related to their role as mothers, regardless of their engagement in paid employment (Lee & Keith, 1999).

Confucianism also shapes the lives of present-day persons with disabilities in South Korea. Individuals with disabilities have been stigmatized in Korea partly because they are viewed as people who threaten reciprocal family ties. Confucianism requires younger generations to give respect to and provide care for older generations (Lee, 1998). Koreans believe that having a disability inhibits an individual's ability to care for aging parents. Having a disability also can limit individual ability to pay respect to ancestors via the practice of *jesah* or the memorialization of ancestors via gravesite ceremonies. Related to the practice of *jesah* is the idea that disabilities occur in the present generation because past generations have chosen inappropriate grave locations for family members or have not taken proper care of their ancestors' graves (Kim & Kang, 2003).

Individuals with disabilities also are less valued in Korean Society because they bring shame to their families by not conforming to societal ideals of success and by threatening the homogeneity of society (Kim & Kang, 2003; Lee, 1998; Yang & Rosenblatt, 2001). Historically, South Korean individuals with disabilities have been dehumanized with words such as *byungshin* or *dungshin*, roughly translated as crippled or retarded. Today, because of work done by disability activists, terms such as *jangaein*



or individuals with disabilities and *jangaewoo* or friends with disabilities are used. These newer terms place emphasis on the personhood of individuals with disabilities rather than on their disabilities. Still, disability is considered a shameful experience for individuals and their families in South Korea (Kim & Kang, 2003).

Though disability continues to be conceptualized as a shameful experience (Kim, 2002; Lee, 1998), recent social movements have improved the lives of individuals with disabilities (Kwon, 2005; Park, 2002). The latest data from the Korean Ministry of Health and Welfare (<http://www.mohw.go.kr/user.tdf>) indicates that over 1.6 million individuals with disabilities have registered for educational and financial services that were not available even as late as the 1970s. Through the 1977 Special Education Promotion Act (SEPA), children and individuals with disabilities became eligible to receive a free and appropriate education (Kwon, 2005; Park, 2002). Since this legislation was enacted, the number of special schools for school-aged children with disabilities has increased. Over 53,000 children with disabilities currently are educated in a variety of settings in South Korea (Park, 2002). Additional therapeutic treatments are provided to children of all ages at no cost to parents. Parents must register their children with the Korean Ministry of Health and Welfare to receive these services. Parents who can afford to do so often pursue and pay for private services, believing that these services are of higher quality than services offered by the government (Jung, 2007). Clearly, both continuity and change characterize the lives of individuals with disabilities living in South Korean.

In this section, we have illustrated how complex gender and disability systems have evolved to produce a unique cultural context within which South Korean mothers

and their children with autism live. Next, we provide an overview of the literature on mothering a child with a disability, both in the United States and in Korea, to lay a rationale for our study.

### Mothering a Child With a Disability

Mothering a child with a disability can be both rewarding and challenging (Marcenko & Meyers, 1991; Read, 2000; Traustadottir, 1991). Beckman-Bell (1981), for example, found that mothering a child with a disability is more stressful than mothering a child without a disability. Mothers who have children with special needs can feel overwhelmed by their responsibilities (Read, 2000; Traustadottir, 1991). For example, mothers caring for children with end stage renal disease feel trapped by their extensive and ongoing caregiving duties, and they believe that these duties limit their autonomy and independence (Nicholas, 1999).

Caring for a child with a disability can be gratifying as well. For example, some mothers of children with disabilities experience a sense of satisfaction and pride when they master medical techniques necessary to maintain their children's health (Nicholas, 1999). Mothers who have children with disabilities sometimes experience a broadening of their identities because of a newfound sense of responsibility for others (Nelson, 2002; Skinner, Bailey, Correa, & Rodriguez, 1999). This larger sense of responsibility can translate into advocacy for children with disabilities (Traustadottir, 1991).

Mothers who have children with disabilities share common experiences, but they also experience mothering within a unique disability context (Gray, 1993, 1994; O'Brien, 2007). Because of the ambiguous nature of autism, mothers of these children experience

substantial levels of stress (Bristol & Schopler, 1984). For example, the causes of autism have not been fully explained, despite its increasing prevalence (Newschaffer, Falb, & Gurney, 2005). Mothers of children with autism often do not know why their seemingly healthy children begin to show signs of developmental delay. Children with autism also vary widely in their intellectual, educational, social, and communication capacities (American Psychiatric Association, 1994; Mauk, Reber, & Batshaw, 1997). The question, “Does my child have autism?” is often difficult to answer. Finally, unlike other developmental disabilities, the physical appearance of children with autism usually does not differ from that of those without disabilities (Mauk, Reber, & Batshaw, 1997). Mothers of children with autism sometimes encounter strangers who blame them for their children’s misbehavior rather than attribute the behavior to the child’s disability (McDonnell, 1998).

In addition to managing a unique disability context, mothers manage their children within a particular cultural context. South Korean mothers who have children with disabilities socialize their children intensively to conform to Korean ideals of success (Cho, Singer, & Brenner, 2003). Academic achievement is emphasized for children with disabilities in the same way that it is emphasized for children without disabilities (Park, Kim, Kim, Lee, Wu, & Jung, 2004). Researchers also have shown that Korean mothers who have children with disabilities struggle because of the discrepancy between their beliefs about how children should behave and the limited success they have changing their own child’s behavior (Kim & Kang, 2003). In Korean society, these

mothers face extensive criticism from strangers for not teaching their children to behave appropriately in public (Lee, S. 2002; Lee, H. W., 1994; Lee & Jun, 2004).

Empirical evidence suggests, then, that mothering a child with autism occurs within particular disability and cultural contexts. Most researchers studying mothers with children who have autism, however, ignore or downplay the influence of sociocultural systems that constitute women's understandings of themselves and their children's disability. Instead, researchers tend to focus narrowly on how mothers cope with the stressful experience of having a child with a disability. This is true for research that takes place in the United States (e.g., Nelson, 2002; Nicholas, 1999) and in South Korea (e.g., Cho, Singer, & Brenner, 2003; Park, Kim, Kim, Lee, Wu, & Jung, 2004). Our aim is to broaden our understanding of mothering a child with autism by focusing on the interplay between sociocultural belief systems related to being a "good" mother and a "normal" child and the ways that mothers conform to and resist these systems.

### Theoretical Framework

To understand the dialectic interaction between sociocultural systems or discourse and agency, we integrate several unique but related theories. A social constructionist perspective provides the overarching epistemological framework for the study (Burr, 2003; Schwandt, 2000). The origins of this perspective can be traced to symbolic interactionism in that it emphasizes the connection between language and social interaction (Gubrium & Holstein, 2000; LaRossa & Reitzes, 1993). Schwandt (2000) argues, however, that social constructionism is unique because the theory highlights how individuals play an active role in the process of creating meaning. Social constructionists

also attend to discourses that are made up of both cultural and material practices that shape individuals' understandings of themselves and their relationships (Burr, 2003; Schwandt, 2000; Smith, 2003). For example, both Confucianism and Korean women's responsibility for unpaid care shape mother's understandings of themselves and their children with disabilities.

We used feminist and disability rights theories to pay particular attention to the ways women's everyday lives were shaped by systems of power related to gender and disability. By focusing on previously ignored aspects of female life, critical feminist theorists work to correct "both the invisibility and distortion of female experience in ways relevant to ending women's unequal social position" (Lather, 1991, p. 71). In essence, feminists attempt to explain women's historical oppression by accounting for political, economic, cultural, and psychological forces that support it. Caring for young children is undervalued work in South Korea (Oh & Kim, 1996) and it is work that is almost entirely the responsibility of women (Cho, 1998; Yang & Rosenblatt, 2008). Still, some evidence suggests that South Korean women are beginning to resist traditional values that require them to sacrifice their own lives to raise children (Duncan, 2002; Hyun, 2001). We sought evidence of both conformity and resistance to the dominant gender system in Korea via stories mothers told about their lives with children with autism.

Disability theory added to our thought by providing a way to critique dominant sociocultural narratives that devalue children with autism in Korea. Disability theorists argue that the inferior social status given to individual with disabilities does not result from bodily defects, but rather to "myths, fears, and misunderstandings that society

attaches to them” (Murphy, 1995, p.140). Goffman (1963) posited that individuals with disabilities experience stigma, a social process that dishonors and shames them. He also argued that family members and friends can experience stigma via their close ties with those who have disabilities. In this study, we analyzed mothers’ stories for evidence of shame and pride related to their children with autism.

### Method

To understand how mothers conform to and resist dominant sociocultural discourses related to gender and disability, we conducted in-depth interviews with 14 women. This method provided a way to investigate how women understand their everyday experiences (Creswell, 2003; Gilgun, 1992) and it allowed us to highlight how reality is constructed via sociocultural processes (Denzin & Lincoln, 2000). Our method is also rooted in phenomenology in that we assume people actively construct their worlds and themselves through the creation of symbolic and representational stories or narratives (Bruner, 1986; White & Epston, 1990).

### *Sampling*

Because we were interested in dominant beliefs about gender and disability in South Korea, we used a purposeful sampling method called theory-based sampling (Patton, 2002). In this method, participants are selected on the basis of their potential representation of important theoretical constructs. We sought to select mothers of children with moderate levels of dysfunction because maternal experiences vary depending on the level of a child’s autism (Gary, 1993, 1994). We also chose to limit the range of disability because we hypothesized that the level of stigma a mother experiences

is associated with the level of her child's disability. Because mothers typically learn of their child's diagnosis by the time their child reaches the age of three (Mauk, Reber, & Batshaw, 1997), we sought mothers whose children were slightly older. We did so to ensure that we recruited mothers who had moved beyond the initial stages of adjustment to their children's disability. With these criteria in mind, we asked professionals working with children with autism in public schools, childcare settings, and private agencies to distribute packets to mothers whose children had a diagnosis of autism and a moderate level of communication dysfunction. We also focused on children who were between five and nine years of age. Professionals circulated 60 packets on our behalf. Mothers who were interested in learning more about the study were asked to notify either the professional who distributed the packet or to send a pre-stamped letter of interest back to the first author. A total of 19 women responded to our request.

We intentionally narrowed the social context in which participating mothers live because socioeconomic class and geographical location shape the ways that women make sense of themselves and their children (e.g., Lareau, 2003). We purposefully selected middle-class mothers living in urban areas for the study. The first author telephoned interested women to determine their eligibility for participation. Eligibility criteria required mothers to (a) reside in an urban area, (b) be married to the biological father of the child with autism, (c) have at least an associate's degree, and (d) be in a professional or managerial position or be in a relationship with someone who is in a professional or managerial position.

### *Participants*

Fourteen South Korean mothers were eligible for participation. All of the mothers were married and had obtained at least an Associate's degree. Two of the mothers were employed, one full-time and one part-time. All of the fathers were employed full-time in professional or managerial positions. The mothers' household incomes were around or above the South Korean median household income of 2.7 million won (<http://kosis.nso.go.kr/>). On average, these women were 37 years old (ranging from 32 to 43 years). Their children with autism were, on average, seven years old (ranging from 5 to 9 years); nine of the children were boys and five were girls. To ensure confidentiality of participants and their children, pseudonyms are used.

#### *Interview & Translation*

The first author conducted in-depth interviews with participants in their own homes or in locations the women chose. Consistent with feminist methodology, this approach served to minimize the hierarchical relationship between the researcher and the researched (Fontana & Frey, 2000; Smith, 2000). Each participant spent an average of two and a half hours talking about her life. Interviews were conducted in Korean and resulted in a total of 34 hours and 25 minutes of discussion.

Congruent with our interest in understanding how women view their lives, we asked mothers to tell stories of their child's birth and diagnosis. We asked questions such as: (a) Who first noticed something was different about your child, and (b) How was the diagnosis of your child made? Mothers also had freedom to discuss issues that were of concern to them. For example, they described what their lives were like with a young child with autism. The second part of the interview asked mothers to explain how they



and others understand what it means to be a good mother and what it means to be a child with autism. We asked questions such as: (a) What do you think makes a good mother, and (b) What do most people think about children with autism spectrum disorders?

Mothers received a 10,000 won (\$10) gift certificate as a symbol of our gratitude for their time and effort.

All interviews were tape-recorded, transcribed verbatim, and translated into English by the first author. Next, both authors read and discussed each translated transcript to ensure that the first author, a Korean American who was born and raised in South Korea, and the second author, a European American, understood the meaning participants were conveying in their interviews. Also, because English is the first author's second language, the second author reviewed and edited the transcripts to ensure that they accurately reflected the mothers' stories in English. This editing process was done in cooperation with the first author.

### *Data Analysis*

Using social constructionist, critical feminist, and disability theories, we analyzed South Korean mothers' understandings of themselves and their children with autism in relation to sociocultural ideas of what it means to be a "good" mother and a "normal" person. Answers to the following research questions were sought: (a) How do sociocultural systems related to mothering and disability, particularly autism spectrum disorders, shape South Korean mothers' understanding of themselves and their children with disabilities; and (b) How do these mothers resist and/or conform to dominant discourse about being a "good" mother and a "normal" child?

In the initial phase of our analysis, individually and together, we read each transcript to identify and label significant concepts related to gender and disability (Charmaz, 2006). To enhance our theoretical sensitivity (Strauss & Corbin, 1990) we asked: (a) How do the participants define good motherhood, and (b) In what ways do their stories argue against this definition? We also asked: (a) How do they think and feel about their children with autism, and (b) How do their stories deviate from dominant ideas of success in South Korea? From these questions, we determined initial theoretical concepts. Examples of these concepts are managing sympathy and pity, accepting blame, and raising a successful child with autism.

During the focused coding phase of our analysis, we paid special attention to how definitions of normality and abnormality in both gender and disability relations served to establish boundaries of acceptable beliefs for the women in our study. In turn, evidence of resistance to sociocultural boundaries was sought (Gavey, 1989). Each woman's story also was compared and contrasted to the other stories to determine similarities and differences among the women. Through this process, we used the technique of negative case analysis to verify our main themes and to elaborate variation within themes (Strauss & Corbin, 1990).

### Themes

South Korean mothers understood themselves and their children with autism within a sociocultural context that requires mothers to provide high levels of nurturance and support to their children and conceives of disability as a shameful experience for both individuals with disabilities and their family members (Kim & Kang, 2003; Lee, 1998).

Within this context, women struggled to transcend the shame they experienced. Even though strangers and family members blamed them for their children's disability, these mothers told of ways that they had begun to redefine what "normal" means for children with autism in Korean society. These same mothers, however, did not challenge the meaning of "good" motherhood. All of the women believed that their success was tied to their children's success, and their stories highlighted their efforts to help their children with autism succeed. A few of the mothers argued that they were justifiably limited in their success because of their children's limitations. Mainly, though, the women accepted their mothering responsibilities.

*Resisting Shame: "I Don't Pay Attention to How Others Look at Me"*

All 14 mothers in our study were aware of negative attitudes strangers held toward their children with autism. Although South Koreans increasingly are aware of individuals with autism, they explained that prejudice still exists. Ten mothers stated that most people think their children are "dumb, slow, or poor." Mothers told of how they regularly see strangers give their children with autism "a look," indicating that the children are inferior to others. Kyung-Sook, 36, felt that others looked at her son as if he were an "animal in the zoo." Sun-Hee, 38, explained that because her child's size does not match his maturity level, people "tend to think that he's an idiot." Jung-Min, 35, believed that "There are people who still think that children with autism should stay home."

Four mothers believed that people fear children with autism. According to Mi-Ran, 35, some people are frightened because of worry about potentially aggressive

behaviors. She explained: “Most people have a difficult time getting close to [children with autism] because of their problematic behaviors.” Sun-Hee, 38, agreed: “Other mothers might worry that our children will harm their children.” All of the mothers in our sample had empathy for the concerns of strangers. Ji-Woo, 37, summarized it this way, “You don’t know about [autism] until you spend a lot of time with [someone who has autism].”

Though the mothers had empathy for the concerns of others, they also experienced tension during encounters with strangers. Eleven mothers noted that public outings were problematic because of the discrepancy between their children’s appearance and their children’s behavior. Strangers did not automatically understand that their children were behaving inappropriately because of a disability. This discrepancy brought about a situation in which the mothers had to decide whether to share their child’s diagnosis or maintain their own and their child’s privacy. Sun-Hee, 38, found these repeated interactions tiring: “If he misbehaves in front of others who don’t know about him, I don’t want to have to explain to them over and over that ‘My child has a developmental disability.’” Jung-Min, 35, eventually decided to ignore how others looked at her daughter and herself. She stated, “It used to bother me. These days, I don’t pay attention to how others look at me. I don’t care.”

Two mothers discussed times in which they had to defend their children or themselves from inappropriate reactions from strangers. Hae-Jung, 36, remembered a time when she encountered strangers who assumed her son was crazy. She saw a boy talking to his father, making a gesture in which he circled his index finger by his head,

indicating that her son was crazy. As she walked out of the restaurant, she looked at the father and the son and told them firmly, “My son doesn’t have a mental illness.” Another mother, Hee-Yeon, 39, told of a time in which she uncharacteristically raised her voice to an older woman who had scolded her daughter for throwing soap at others in a public sauna. When the woman accused Hee-Yeon of not properly teaching her child to behave, she replied, “Shut your mouth!”

Four mothers in our study not only managed difficult interaction with strangers, but also dealt with husbands and in-laws who blamed them for their children’s problems. When Hae-Jung, 36, and her husband were struggling to understand their oldest son’s problem, her husband blamed her:

My husband gave me a book and told me to read it. His point was that I didn’t raise our child right. I am not very talkative and I don’t talk much to the kids either. My husband was saying that moms should give lots of stimulation to their kids. But I didn’t do this and, consequently, our child turned out like this.

It was not much different for Eun-Hae, 32. Both her husband and her parents-in-law accused her of not raising her daughter properly, “My husband blamed me. He said that it was my fault because I didn’t raise her right. My in-laws were saying the same thing.”

Mi-Ran, 35, remembered, “The whole family’s blame came down on me. My in-laws pointed their fingers at me, saying that he was like this because of me.”

Nine mothers said that they initially blamed themselves for their children’s disabilities. Yoon-Ju, 36, said, “I kept asking myself, ‘What did I do wrong?’” Sang-Mi, 37, remembered learning about her daughter’s disability: “I thought that I was too negligent of her.” Kyung-Sook, 36, said, “I realized that it all happened when he was

really young. I neglected him.” Another mother, Hae-Jung, 36, agreed: “If I had interacted with him a little bit more, he would be doing much better.”

Half of the mothers struggled with depression when they first learned of their children’s autism. Yoon-Ju, 36, remembered, “I cried for about 6 months. Day after day, I cried.” Ji-Woo, 37, explained: “I think I had depression.” Six mothers in our study indicated that suicide was an option that they had considered during this initial time of adjustment. Hee-Yeon, 39, said, “I wanted to die by jumping to the ground from this 10<sup>th</sup> floor.” These mothers explained that if they had committed suicide, they also would have killed their children with autism. Kyung-Ju, 43, stated, “There was no reason to die without my child.” Hae-Jung, 36, also thought of ending her son’s life and her own life. She later came to realize, though, that it was her problem not her son’s problem. She stated, “I thought about it a lot. I used to think he was miserable, but then I realized he may be happy with his life.”

Though all of the mothers struggled with negative attitudes present in South Korean society, 10 mothers resisted these prejudices. For example, 5 of these women refused to accept pity from their friends and family. Sang-Mi, 37, remembered a time when she told a friend, “We’re not that miserable. Sometimes I am happy too. Maybe the degree of happiness might be different, but I think I am happy enough.” Mi-Ran, 35, stated: “I don’t like when others feel sorry for us. Honestly, I want others to look at him as he is.” Instead of hiding their children with autism, 5 mothers integrated their children into their public lives. Jung-Min, 35, interacted with her neighbors this way: “I open my door and let others know about Hyo-Kyung—just as she is.” Another mother, Hae-Jung,

36, said, “I am not embarrassed to talk about him or to go somewhere with him because he has a disability. I didn’t do anything wrong. Why should I hide my child’s disability?”

Kyung-Ju, 43, moved beyond a focus on her own child to a focus on the larger community of individuals with disabilities. She contributed money to organizations that served people with disabilities and she recruited others to do so as well. She stated, “I am interested in human rights for people with mental retardation.” She also spoke in front of the South Korean National Assembly, a group akin to the United States Congress. She explained, “I spoke as a parent representative for assistance with tuition for childcare.”

*Reconstructing Normal Childhood: “I Want Her to Have Good Social Skills”*

All of the mothers went through a process of redefining what normal means for their children with autism. During infancy, they explained, they had thought that their children were developing normally. Kyung-Ju, 43, explained: “All of my children were healthy.” Jin-Young, 38, said: “She looked very smart staring at the mobile or looking at pictures on the wall in her room.” Hae-Jung, 36, stated: “It was hard to pick out something that was different about him.” She elaborated: “Before he was a year old, he said ‘ma.’ So, I thought he was fine.” Jung-Min, 35, also did not notice a problem with her infant: “She didn’t have any problems with her physical development. Actually she controlled her neck, sat up, and walked faster than normal.” Because their children looked and acted like other infants, the mothers assumed that their children would develop in a typical way.

Once they discovered that their children had autism, 10 mothers believed that their children could be cured or could become “normal” through intensive medical and

educational treatments. Sun-Hee, 38, stated: “I believed that if I did my best for Dong-Kun for a year, whatever it was, he would become the same as a normal child.” Hae-Jung, 36, said that she tried Chinese medicine and acupuncture to cure her son’s autism. She explained: “We thought that he might be cured. So, we held him down for the doctor to place 30 needles all over his body. He was crying so hard. We were so foolish.” Eun-Hae, 32, also said that she believed that her daughter could change: “Until she was 6 years old, I thought that she might be normal when she grew up. But now I do not think that she will become normal.” When Jin-Young, 38, found out about her daughter’s disability, she explained: “I thought my child would be cured if I followed everything that was recommended.”

During this time, 11 of the women’s connections to other mothers who have children with autism helped them to become reconciled with their children’s limitations. Hae-Jung explained that she gained emotional support from other mothers whose children have autism: “I am not the only one who has pain and difficulty.” Ji-Woo, 37, stated: “It is easier for me to talk to other moms who have children with disabilities.” Sun-Hee, 38, explained: “We all share the same issue—our children.” Kyung-Ju, 43, said: “I learned from other mothers.”

As the mothers confronted their children’s limitations and learned more about autism, they adjusted their expectations of success for their children. Rather than focusing on academic success, seven mothers emphasized the importance of teaching social and communication skills to their children with autism. Their hope was that their children will be included in society. So-Hyun, 37, stated: “What I want for Ho-Seok is that he can



communicate with others.” Jung-Min, 35, agreed: “To live in this society, [my daughter] needs to be able to communicate what she wants.” Jin-Young, 38, had a similar goal for her daughter: “I want her to have good social skills and be included in society.” Sun-Hee, 38, talked about her expectation this way: “Teaching Dong-Kun to live without harming or hurting others in society. I think that it is my current goal.”

Unlike the very goal-oriented approach that most South Korean mothers use with their children, four mothers in our sample did not have specific goals for their children. Instead, they wanted their children to be happy. When asked about her expectations for her son, Ji-Woo, 37, said, “Maybe when he is a little bit older, he will do something that he likes. I just want him to do whatever he wants to do.” Jung-Min, 35, said that she wants to raise her child “to be psychologically comfortable and physically healthy.” Yoon-Ju, 36, explained: “Even if he has autism, he can still do whatever he likes to do.” She described her childrearing philosophy in this way: “I focus less on education and more on play.” In addition to communication skills, So-Hyun, 37, stated: “I just want him to enjoy his life.”

Three mothers had a goal in mind but the goal was shaped by their children’s circumstances. These mothers wanted their children to live semi-independently or independently. Kyung-Ju, 43, said, “He can live near me in a duplex. I can live upstairs and he can live with his friends on the lower floor. I hope he can live in a group home in our community.” Eun-Hae, 32, stated: “I really want her to live independently, somewhere without me. I worry about that most. That is my goal.” Sun-Hee, 38, asked

“What kind of work can he do so that he can live independently without his mom and dad? What can we do to help him be independent?”

Not only did mothers redefine what it means to be normal for their children with autism, but also 4 mothers redefined success for their children without disabilities.

Kyung-Ju, 43, for example, encouraged her oldest daughter to attend a high school that focused on animation skills rather than a school that emphasized more highly regarded subjects such as math, science, and literature. She stated, “I respect my children’s opinions as much as possible.” Another mother, Hae-Jung, 36, explained, “I don’t believe that my children should do something well or that I should raise them successfully. I don’t think that parents have the right to force their children to study harder to make them successful.” Sun-Hee, 38, talked about her daughter without a disability in this way: “She may find something that she likes instead of me pushing her to become something I want her to be.” So-Hyun, 36, criticized the way her friend pressured her daughter to become a doctor: “What if she doesn’t want to be a doctor? I just tell my children, ‘Be whoever you want to be.’”

*Being a Good Mother: “It Depends On How Successful Our Children Are”*

Though the women in our sample described ways in which they had begun to redefine what it means to be a normal child in Korean society, most of the women showed little evidence of transforming their ideas about what it means to be a good mother. They explained that in South Korea, a mother’s success is equal to her child’s success. When a child receives good grades, goes to a prestigious university, and finds a lucrative job, most Koreans believe that this success results from the successful practices

of the mother. According to Mi-Ran, 35, “When children grow up successfully, people think ‘This mom is great. It is about looking at the results.’” Kyung-Sook, 36, agreed: “A mom who raises her child to be a famous musician or a genius is considered to be a wonderful mom. It depends on how successful her children are.” Because mothers are evaluated by their children’s success, Kyung-Hee, 42, explained that Korean mothers “push [their] kids to work harder and harder” so that their children can go to prestigious high schools and universities.

When asked what makes a good mother to a child with autism, all 14 women talked about Jin-Ho’s and Hyung-Jin’s mothers, women portrayed in Korean media as successful mothers of sons with autism. Jin-Ho and Hyung-Jin are teenagers with autism who have won multiple sports competitions. Their mothers have received significant attention because of their success, and the personal stories of both mothers and their sons have been made into television shows and films (Lee, 2005). In addition, Jin-Ho’s mother wrote several books about her devotion to her son and her educational strategies to train him. She travels across Korea, explaining her strategies to other mothers with children who have autism. According to So-Hyun, 37, most people believe that a good mother to a child with autism is someone like “Jin-Ho’s and Hyung-Jin’s moms. Those moms are persistent in their efforts to help their children.” Eun-Hae, 32, who read one of the books written by Jin-Ho’s mother, said that “Most people think of them as good moms.” She continued to explain how devoted this mother was:

She recorded everything about him and monitored every detail of his problematic behaviors. She did individualized education, which was different from how others do. There were lots of things that she actually did by herself. Her focus was on Jin-Ho.

All 14 women said that they admired these model mothers. Hae-Jung, 36, said, “Everyone wants to be like them. They are our idols! I think to myself, ‘Will my son be a swimmer like Jin-Ho? Or will he become a marathoner like Hyung-Jin? Will I become like their moms?’” Another mother, Sun-Hee, 38, talked highly about the educational and behavioral strategies that these mothers used to train their children: “I was actually pretty envious of them. I still think, ‘Wow, such a mom exists!’ Not that I’ve exactly followed her ways. It is kind-of my dream.” In comparing herself with these idol mothers, So-Hyun, 37, said that she felt sorry for her son: “I am sorry that he met the wrong mom. He could have gotten better if he had met a mother like them.”

Though all of the mothers admired Jin-Ho and Hyung-Jin’s mothers, 6 indicated doubt about the standards these women set. They stated that media representations of the women created a false image of what mothering a child with autism is really like. Yoon-Ju, 36, described the media stories in this way:

These children can make progress when their moms help them. Most people misunderstand that most children with autism are not like Jin-Ho and Hyung-Jin. Maybe they are in the upper 1%. Most children with autism are worse. These mothers were successful because their children had some abilities to do well with support.

Sang-Mi, 37, felt that “Children need to meet good parents, but moms also need to meet good kids.” These 6 mothers reduced the pressure to be ideal by highlighting that not all children with autism are capable of high success. Kyung-Sook, 36, recognized that financial support was necessary for mothers to raise their children with autism successfully. When her brother suggested that she was not meeting the standards of these famous mothers, she replied firmly: ‘It requires financial support. And other things are

sacrificed. This is the reality. I said, ‘Wasn’t Jin-Ho’s dad a doctor? Wasn’t he an only son?’

Although some mothers questioned the high standard of mothering a child with autism, all 14 of the women told stories that highlighted their responsibility for their children. They explained that they engaged in an intensive practice of *following*. The mothers explained that *following* meant that they persistently walked behind their children to anticipate their every action. Jin-Young, 38, explained, “I direct all of my attention to her. I try to read her mind.” The practice of following, they explained, required almost 24 hours of vigilance. Hae-Jung, 36, states: “I have to pay attention to him 24 hours a day. I need to know what he is doing. I need to be alert all the time.” All of the mothers told stories of how they spent significant amounts of time and energy to help their children with autism “get better.” Jin-Young, 38, said, “It is difficult, but with education she will get better.” All 14 mothers stated that they worked hard to locate private therapists for their children, despite the fact that public professionals were available to provide services to them. Two mothers stated that they resorted to begging to have their children seen by a particular private specialist. Hee-Yeon, 39, explained, “I said, ‘I feel like I am going to die if you don’t help my child.’”

Though all of the mothers described ways they conformed to South Korean standards of good mothering, two of the women indicated dissatisfaction with their arrangements. Sun-Hee, 38, pointed out the psychological and social oppression that South Korean women experience:

It is about Confucianism and traditional ideas against women that are passed down from generation to generation. When you ask all moms, all women, they say they want to be born as men. There is a lot of inequality.

So-Hyun, 37, stated, “In our country, to be a good mom, you need to sacrifice yourself, though, I don’t want to.”

Despite these few examples, most of the mothers accepted the gender relations in their lives or they had become reconciled to them over time. Mi-Ran, 35, said that she used to be very upset with her husband who did not spend much time with their son, “[He] is not a family guy. He plays computer games all the time. When he comes home after midnight, he doesn’t even look at his son.” Mothers excused their husbands’ behavior by explaining that their husbands did not know how to take care of their children. For example, Sang-Mi, 37, remembered when she was 5 months pregnant, taking care of her oldest child, and doing all of the housework by herself, “My husband is not a very caring type. He doesn’t know how to play with the kids. So, I do it all by myself. I don’t even expect [him to help].” Ji-Woo, 37, thought that her husband did not understand the important details of their child’s life because of his own busy life. She explained that “Men go to work and come home at night. They have dinner and go to bed. [My husband] doesn’t know much about Yu-Min’s behaviors. He doesn’t know how I take care of things.” Instead of emphasizing their husband’s caregiving responsibilities, all of the women stated that their husbands’ role as breadwinner was primary. Their husbands’ ability to provide financial support was particularly important to them because private therapy for their children with autism was expensive.

#### Discussion and Implications

The mothers in our study illustrate how Confucian thought continues to influence the daily lives of women, dictating that mothers accept primary responsibility for raising their children, including children with autism. This finding is congruent with other studies that indicate South Korean men engage in very little unpaid care work (e.g., Budlender, 2007). Most women in our study did not question their mothering responsibilities. As one mother pointed out, “I don’t really think that it is sacrificing. Isn’t it my responsibility?” Though a few Korean scholars have problematized the patriarchal aspects of Confucian thought (Cho, 1998; Duncan, 2002; Kim, 1993), the women in our study focused on being good mothers by raising successful children. Because their children had special needs, they “followed” their children vigilantly and they arranged for their children to participate in private therapies to help them “get better.” To provide this level of care, the mothers did not engage in paid employment. Giving up or limiting paid work are strategies that women in the United States use to raise their children with disabilities (Leiter, Krauss, Anderson, & Wells, 2004; McKeever & Miller, 2004; Porterfield, 2002). The mothers in our study used these strategies as well. Perhaps the women were highly motivated to be successful mothers because it is the primary means by which they can obtain social recognition in South Korea (Kim & Ryu, 1996). The recognition they received, however, was tempered by the fact that their children were not perfect.

All of the mothers in our study were aware of the negative attitudes that strangers and family members alike had toward them and toward their children with autism. Over time, though, they began to resist stigmatizing discourses that define disability as

shameful. The mothers redefined what their goals were for their children and they learned to advocate for them—in the home, in the community, and in the larger society. A primary way that they adjusted their beliefs was through ties to other mothers who have children with autism.

Of course, our sample is small and our participants are similar in that they are married, live in an urban setting, and are middle-class, South Korean mothers. Because of this homogeneity and because of our sample size, generalizing our findings to all Korean mothers who have children with autism would be inappropriate. Still, our study begins to illuminate how sociocultural systems influence South Korean mothers' understanding of themselves and their children. Our findings suggest that middle-class, Korean women can resist sociocultural discourse, particularly that which is harmful to their children, via supportive ties with one another. The impetus for women to resist oppressive belief systems related to motherhood may occur through these same support networks. Feminist family researchers advocate for knowledge that can serve to transform society (Allen, Lloyd, & Few, 2009). To this end, we intend to disseminate our findings to participants and to professionals who assisted us with recruitment, addressing problems identified in the study (e.g., both mothers of children with disabilities and the larger society blame mothers for children's disabilities). Through this effort, we hope to offer Korean mothers and the professionals who work with them an alternative narrative to consider, one that acknowledges women's oppression and empowers them to advocate for themselves as well as their children with autism.



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## CONCLUSIONS

I examined the ways women understand themselves and their children with autism in two cultural contexts: the United States and South Korea. As a whole, the findings of these two studies suggest that middle-class women in both cultural contexts understand their children with autism and themselves through sociocultural lenses related to gender and disability. In this conclusion, I provide summaries of the findings from each study and I discuss their shared significance. Then, I offer suggestions to support the lives of women who have children with autism in both countries. Finally, I discuss the future direction of research needed to better understand the lives of mothers caring for their children with autism.

### Summary of Findings

The first study, *Striving to Be a Better Mother: Women Who Have Children With Autism*, was conducted with Lori McGraw and Katherine MacTavish. Guided by symbolic interactionist and feminist theoretical perspectives, I qualitatively examined (a) how middle-class, White women who have children with autism understand themselves as mothers and (b) how their ideas are shaped by social interactions with others. Through in-depth interviews with 12 women who have children with autism, I found that these women understand themselves as empathic supporters, mediators, and advocates for their children with autism. Their stories are shaped by selective attention to those who support their self-image and a disregard of those who undermine it.

In the second study with Lori McGraw, *The Intersection of Motherhood and Disability: Being a “Good” Korean Mother to an “Imperfect” Child*, I conducted in-depth interviews with 14 middle-class, South Korean women who have children with autism to gain a better understanding of how these women understand themselves and their children with autism within a sociocultural context that devalues mothers and individuals with disabilities. The narratives of the women provide evidence that they resist attitudes that devalue and stigmatize their children with autism by redefining what “normal” childhood means. These mothers did not, however, resist attitudes that devalue women. They continued to perceive themselves as “good” by holding on to Confucian family values that encourage women to sacrifice themselves for their children’s success.

### Conclusions Drawn From Each Study

Although each study in my dissertation was conducted in a distinct cultural context with slightly different theoretical frameworks, the main focus of the studies centers on the understandings mothers who have children with autism have of themselves and their children. The findings of the two studies collectively tell us that mothering a child with autism is (a) gendered, (b) influenced by the stigmatized nature of autism, and (c) simultaneously oppressive and empowering to women. In the following sections, I detail these aspects of mothering a child with autism.

#### *The Gendered Nature of Caring for a Child With Autism*

The experiences mothers have caring for their children with autism are shaped by sociocultural processes related to motherhood. As feminist scholars have long



argued, gender is a socially constructed rather than biologically given concept (Bernard, 1974; Oakley, 1974; Osmond & Thorne, 1993; Thompson & Walker, 1989). Women's identities and experiences are shaped by sociocultural beliefs about what it means to be a mother (Arendell, 2001; Glenn, 1995; Hays, 1996). The women in the first study, *Striving to Be a Better Mother: Women Who Have Children with Autism*, understood themselves and their mothering a child with autism through paying attention to their social ties. These White American women pursued relationships that support their mothering a child with autism while they discontinued relationships that threaten their ideas. A similar social process was shown in the second study, *The Intersection of Motherhood and Disability: Being a "Good" Korean Mother to an "Imperfect" Child*. The ways that Korean mothers understood themselves and their children with autism were closely related to Confucian beliefs about disability and the proper role of women in the culture. These mothers accepted their role as primary caregivers for their children. They did so without much questioning of their husband's lack of involvement in child rearing. Furthermore, as the social status of mothers is highly dependent on the outcome of their children in South Korea, the mothers in the study were highly engaged in the pursuit of treatments to help their children "get better."

#### *Mothering Within Cultures That Stigmatize Persons With Autism*

The ways mothers understand themselves and their children with autism is not only gendered, but also is shaped by sociocultural processes related to disability. Mothers often struggle with the ambiguous nature of autism in that their children

appear to be physically healthy but are delayed in their cognitive, social, and language development (Gray, 1993, 1994, O'Brien, 2007). Mothers' understanding of autism is also related to how individuals with autism are viewed in their society (Skinner & Weisner, 2007; Whyte & Ingstad, 1995). For example, the way that women in Oregon understood autism was shaped by their interactions with extended family members, friends, and professionals. The way that South Korean mothers understood autism was influenced by their culture's belief that having a child with autism is shameful.

As an empathic support to their children with autism, the women in Oregon accepted their children and their disability and made efforts to be patient with their children with autism. They also engaged in educating their relatives, friends, and neighbors so that others have accurate information about their children with autism. The South Korean mothers also experienced challenges in understanding autism. Their understanding of autism prior to their children's diagnosis was limited to stereotypical images of someone with severe autism. Additionally, their children's typical appearance did not match with the problematic behaviors that their children exhibited. Rather than attending more to a medical or educational explanation for their children's disability, these mothers felt humiliated by shame that is typically associated with individuals with autism in Korean society (Yang & Rosenblatt, 2001).

#### *The Two Sides of Mothering: Oppression and Empowerment*

My dissertation continues the discussion about how mothers can be both oppressed and empowered (Arendell, 2001; Glenn, 1994). Because of their children's disabilities, women in my studies seemed to be more pressed to meet cultural

expectations of being a caring mother. They were influenced by the patriarchal idea that women are mainly responsible for nurturing their children with disabilities (Read, 2000; Traustadottir, 1991). For example, the Oregon mothers indicated that they tried harder than mothers with typically developing children to be good mothers. The same was true for the mothers in South Korea. They were blamed by family members for their children's problems, and they worked extremely hard to find a way to help their children "get better."

In contrast, mothers may hold a positive image about themselves when they meet high standards for mothering (Skinner, Bailey, Correa, & Rodriguez, 1999). In addition, women can feel empowered to advocate for the needs of their own and other children with disabilities (Read, 2000; Traustadottir, 1991). The stories of the mothers in the first study indicate that they selectively paid attention to reassuring comments that they are caring for their children well. These women sought second opinions when relatively powerful medical and educational professionals discredited their own concerns and knowledge about their children. Although the South Korean mothers seldom resisted sociocultural ideas related to being a "good" mother, they resisted ideas that were hurtful to their children by building supportive relationships with other mothers who have children with disabilities.

### Implications for Practice

The findings of these studies illustrate that women primarily think of themselves as "good" when they accept dominant sociocultural ideas that hold them responsible for their children's care--both in the United States and in South Korea.

Here, I offer several implications for practice to support mothers and to encourage fathers to share responsibility for providing care to their children with autism. To be effective, each approach requires a sensitive adaptation to the cultural context within which women live.

*Recognizing Mothers' Care Work and Encouraging Fathers' Care Work*

Women can benefit from social recognition of the gendered nature of care work (Read, 2000; Traustadottir, 1991). Educational and support programs can serve to address how care work is unequally divided between women and men and the effort to change the family care work pattern (Dillaway & Paré, 2008).

Current support programs for families who have children with disabilities focus on providing information on services for children and training for parents (Matthews & Hudson, 2001). These programs tend to use gender-neutral terms, such as parent. For example, the U.S. Department of Health and Human Services (<http://www.disabilityinfo.gov/digov-public/public/DisplayPage.do?parentFolderId=5252>) provides an extensive list of programs that include The Arc-Parents with Intellectual Disabilities, Family Support 360, Parent Training & Information Centers, and Community Parent Resources Centers. These programs emphasize the development of parental skills to reduce stress and increase coping. Instead of this gender-neutral approach, programs should recognize the work that mothers do as primary caregivers. With this acknowledgement, program providers can not only support mothers but also encourage fathers' involvement in providing care to their children with autism. This issue is equally or

even more urgent in South Korea because of sociocultural beliefs that overlook the unequal division of care work between women and men (Cho, 1998; Lee & Keith, 1999; Yang & Rosenblatt, 2008).

### *Optimizing Mothers' Agency and Resiliency*

Women caring for their children with autism also can benefit from programs that encourage their agency and resiliency. This issue is complex though because mothers and the larger society often put children's needs before women's needs. This focus is more prevalent when children have a lot of needs. Consequently, the well-being of mothers receives scarce attention when they have children with disabilities.

One of the ways to support women is to help them build support networks with other women who have children with autism. The mothers in both studies stressed that their relationships with other women who have children with disabilities were helpful to them. Although mothers seem to find other women in similar situations through informal networks, organized programs can be effective as well. These formal programs can assist women with information and resources useful for mothering their children, and can help women recognize their own worth. For example, a U.S. program such as Parent-to-Parent helps mothers caring for their children with disabilities by matching a veteran mother with a novice mother in a similar situation (Santelli, Turnbull, Marquis, & Lerner, 1997; Santelli, Turnbull, & Higgins, 1997). South Korean mothers could also benefit from this program.

Another way to support women who have children with disabilities is to provide them with respite care. Respite care provides mothers time away from

immediate care responsibility for their children (Chan & Sigafos, 2001; Herman & Marcenko, 1997). In fact, previous studies show that respite care reduces the stress and depressive symptoms of U.S. mothers who have children with developmental disabilities (Chan & Sigafos, 2001; Herman & Marcenko, 1997). Government funded respite care, however, is not readily available for mothers in South Korea (Lee & Kang, 1997). In South Korea, instead of using government funded and implemented programs, mothers often rely on informal networks or voluntary associations such as church groups for provision of care to their children with disabilities (Kim & Ross, 2008). Indeed, none of the South Korean women in the second study mentioned that they used respite care. The availability and implementation of respite care could help South Korean women to psychologically and physically distance themselves from the difficulties associated with care demands.

#### *Reshaping Relationship With Professionals*

Women who have children with autism can benefit from supportive ties with professionals who work with their children. In particular, professionals in the medical sector need to be educated about the signs of developmental delay in young children and the need to pay attention to mothers' concerns about their children.

Incorporating a brief screening for autism into pediatricians' routine well baby care protocols in both the United States and South Korea would greatly enhance early detection of autism. Although the American Academy of Pediatrics (AAP) (<http://www.aap.org/publiced/autismtoolkit.cfm>) is committed to early identification of autism in young children, the implementation of this proposal has been limited.

Autism screening is not readily practiced among most pediatricians in the United States (Johnson & Meyers, 2007). This issue is not emphasized in the Korean Pediatrics Academy (<http://www.pediatrics.or.kr/index.html>). Pediatricians and primary care doctors need to listen to mothers about their concerns related to delayed development in their children (Johnson & Meyers, 2007). It is important not to discredit mothers' own experiences and knowledge about their children.

#### *Increasing Awareness of Autism*

Lastly, mothers and children with autism would benefit from a greater public understanding of autism. Appreciating the various functional and communicative levels of children with autism will help people to be supportive when their family members, friends, and neighbors have a child with autism. Autism is a spectrum disorder and children with autism have various levels of intelligence, language, and daily functions (Mauk, Reber, & Batshaw, 1997; O'Brien, 2007). For example, public campaigns to educate the public should be continuously available. Also, support programs for extended family members to help them understand their grandchildren, nephews, and nieces with autism are needed.

In addition to having national and local programs to help people understand children with autism, it is time to eliminate the stereotypical image of someone with autism as a person with extraordinary intellectual capabilities when most individuals with autism are developmentally delayed. This image creates a false understanding of someone with autism. Especially for South Korean mothers, it is important not to exaggerate the potential success of their children with autism. Although the stories of

Jin-Ho and Hyung-Jin and their mothers might have helped the general public to become more aware of children with autism, focusing only on children with high functioning autism creates a false image of someone with autism and mothers who care for their children with autism.

#### Future Directions

The studies in my dissertation together illustrate the ways mothers in the United States and South Korea understand themselves and their children with autism. Although the stories of the women are unique to their historical, political, and sociocultural contexts, they share similar experiences in that both U.S. and Korean mothers are primary caregivers for their children with autism in societies that devalue care work and children with autism. To better understand mothering a child with autism, my next step will be to compare and contrast the stories shared by the women in South Korea and in the United States. This cross-cultural research approach will better address the similar ways and the unique ways that women understand themselves and their children with autism.



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## APENDICES

## Appendix A

### Inventory for Severity of Autism Spectrum Disorders

The purpose of this inventory is to obtain information about the severity of the condition of a child with autism spectrum disorders. This inventory was developed by modifying the diagnostic criteria for autistic disorders of the Diagnostic and Statistical Manual of Mental Disorders 4<sup>th</sup> edition (DSM-IV).

1. Birthday of the child (MM/DD/YY): \_\_\_\_\_

2. Gender:            Male                                  Female

3. Medical or Educational Diagnosis: \_\_\_\_\_

4. When was the child diagnosed? (MM/YY) \_\_\_\_\_

5. How does the child do in the following areas?

<u>Areas</u>		<u>Rarely</u>		<u>Sometime</u>		<u>Always</u>
Social Interaction	Uses nonverbal interactions (e.g., eye-to-eye gaze)	1	2	3	4	5
	Shows age appropriate peer relationships	1	2	3	4	5
	Shows social and emotional reciprocity (e.g., exchange greeting)	1	2	3	4	5
	Shares enjoyment or interests with other people	1	2	3	4	5

<u>Areas</u>		<u>Rarely</u>		<u>Sometime</u>		<u>Always</u>
<i>Communication</i>	Uses verbal communication	1	2	3	4	5
	Initiates communication	1	2	3	4	5
Communication (continued)	Repeats certain words or phrases	1	2	3	4	5
	Participates in make-believe play	1	2	3	4	5
Stereotyped Behaviors	Flexible with changes in routine	1	2	3	4	5
	Repeats certain behaviors (e.g., hand flapping)	1	2	3	4	5
	Shows intense interests or focuses on something over a long period of time	1	2	3	4	5
	Shows interests or focus on parts of objects	1	2	3	4	5

Appendix B  
Screening Questions for Eligibility

Thank you for your time and interest in the study. I have some questions to determine your eligibility for the current study. I will read questions and choices to you, and you can choose an answer that explains your situation most appropriately.

I will ask you about your child who has autism. Then I will ask questions about you and your spouse. Do you have questions so far?

1. Do you have at least one child who is diagnosed with autism?
  - a. Yes
  - b. No
2. When is the child's birthday? (MM/DD/YY)
3. What is the birth order of the child?
4. Is the child a boy or a girl?
5. When was he or she diagnosed with autism? (MM/YY) How old was he or she at the time of diagnosis?
6. How does he or she do in the following areas? (Inventory of severity of autism spectrum disorders)
7. How have professionals described your child's condition?

Now, I will ask some questions about you and possibly about your spouse.

1. First, how much education have you completed up till now?

- a. No High School Diploma nor GED
- b. High School Diploma (or GED)
- c. Associate Degree
- d. Bachelor Degree
- e. Masters Degree or Above

2. Are you currently employed?

- a. No
- b. Yes

2.1. If you are employed, can you tell me what types of work you do? How many hours per week do you work?

3. Are you currently married?

- a. No
- b. Yes

3.1. If you are married, can you tell me how much education your spouse has completed up till now?

- a. No High School Diploma nor GED
- b. High School Diploma (or GED)
- c. Associate Degree
- d. Bachelor Degree
- e. Masters Degree or Above

3.2. If you are married, is your spouse currently employed?

- b. No
- c. Yes

3.3. If your spouse is currently employed, what type of work does he do? How many hours per week does he work?

4. How would you describe your race or ethnicity?

4.1. How would you describe your spouse's race or ethnicity?

Thank you for answers. You will receive a call from me about your eligibility within a few days. You may or may not be selected for the current study depending on the criteria we are looking for. If your situation meets the criteria of the study, you will be asked to schedule an interview.

In case you are not eligible for the current study, would you be still interested in hearing from us for another study?

YES

NO

Thank you very much again.



Appendix C  
Interview Protocol

*Mothering a Child with Autism Spectrum Disorder*

1. The birth of a child is often an experience mothers remember well. Can you tell me about the birth of your child?
2. How was the diagnosis of [insert the diagnosis] made? Who first noticed something was different about your child? Had you heard about autism before your child's diagnosis? How much did you know about autism before the diagnosis?
3. How have your expectations for your child changed, if at all, as a result of his/her diagnosis?
4. In what way, if any, did your ideas about yourself change from before to after you had your child with ASDs?
5. What did 'being a mother' mean to you before your child was born? What does 'being a mother' mean to you now?

*Discourses related to good mothering*

1. What do most people think makes a good mother? Are there other ways that people think a woman can be a good mother?
2. What do most people think makes a bad mother? Are there other ways a woman can be thought of as a bad mother?
3. In your personal view, what makes a good mother? A bad mother?

4. Has having a child with ASD influenced your view of what makes a good mother? If so, how? Has having a child with ASD influenced your views of what makes a bad mother? If so, how?
5. What do you think that your relatives (e.g., husband, parents, parents-in-laws, and cousins) think makes a good mother to a child with a disability? How do these ideas influence your view of your own mothering, if at all?
6. What do you think that professionals (including teachers) think makes a good mother to a child with a disability? How do these ideas influence your view of your own mothering?
7. What do you think neighbors and friends think makes a good mother to a child with a disability? How do these ideas influence your view of your own mothering?

*Discourses related to disability, especially autism spectrum disorders*

1. What did you think about people with disabilities before your child was born?  
What do you think now?
2. What do you think that your relatives (e.g., husband, parents, parents-in-laws, and cousins) think about people with disabilities? How do you know?
3. What do you think that professionals (including teachers) think about people with disabilities? How do you know?
4. What do you think your neighbors and friends think about people with disabilities? How do you know?

5. What did you think about people with ASDs before your child was diagnosed?  
What do you think now?
6. What do you think that your relatives think about people with ASDs? How do you know?
7. What do you think that professionals (including teachers) think about people with ASDs? How do you know?
8. What do you think that your neighbors and friends think about people with ASDs? How do you know?

Appendix D  
Demographic Information

Participant Identification Number \_\_\_\_\_

I. Participant:

1. Birthday (MM/DD/YY): \_\_\_\_\_

2. Education Level:

- a. No High School Diploma nor GED
- b. High School Diploma (or GED)
- c. Associate Degree
- d. Bachelor Degree
- e. Masters Degree or Above

3. Household Income:

- a. Less than \$24,999
- b. \$25,000 -- 39,999
- c. \$40,000 -- 59,999
- d. \$60,000 – 74,999
- e. \$75,000 – 99,999
- f. \$100,000 more

4.1 Employment:

- a. Not employed
- b. Part time employed less than 20 hrs/wk
- c. Part time employed more than 20 hrs/week but less than 36 hrs/wk
- d. Full time employed

4.2 Type of Work (if employed or previously employed)

5.1 Current Marital Status:

- a. Never Married
- b. Divorced
- c. Widowed
- d. Married

5.2 Educational Level of Spouse (if currently in married relationship)

- f. No High School Diploma nor GED
- g. High School Diploma (or GED)
- h. Associate Degree
- i. Bachelor Degree
- j. Masters Degree or Above

5.3 Employment of Spouse (if currently in married relationship)

- a. Not employed
- b. Part time employed less than 20 hrs/wk
- c. Part time employed more than 20 hrs/week but less than 36 hrs/wk
- d. Full time employed

5.4 Spouse's Type of Work (if currently in married relationship, and spouse is employed)

6. How many children do you have?

7. What is your religious preference?

7.1 If you are affiliated with religious organization, how religious are you?

## II. Target Child:

1. Birthday (MM/DD/YY): \_\_\_\_\_
2. Birth order: \_\_\_\_\_
3. Gender:        Male                      Female
4. Medical or Educational Diagnosis: \_\_\_\_\_
5. When was the child diagnosed? (MM/YY) \_\_\_\_\_
6. What grade level is the child in? \_\_\_\_\_
7. Is your child included in the regular classroom?
8. Is the child receiving any service?

If he is receiving services, then what kinds of services?

Speech Therapy \_\_\_\_\_

Occupational Therapy \_\_\_\_\_

Physical Therapy \_\_\_\_\_

Other services \_\_\_\_\_